

The influence of contextual factors on knee osteoarthritis self-management and education interventions in rural settings of the Western Cape.

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Declaration

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Abstract

Background

Musculoskeletal (MSK) disorders are a global health concern, and the effect of MSK related disability is amplified in rural areas where the community members are affected by their environmental and social situation. The implementation of a self-management and education programme could improve the health outcomes of individuals in these settings, however, the recommendations in the current evidence-based clinical practice guidelines lack description and contextual information. Understanding the specific context could improve the uptake of these clinical guidelines, and therefore improve patient care and health outcomes.

Aim

The aim of this particular study was to describe the contextual factors that could influence the implementation of a self-management and education programme for people with knee OA living in the rural settings of the Western Cape.

Method

A descriptive and exploratory qualitative research method with a phenomenological approach was used to conduct this study. In-depth semi-structured individual interviews and focus group discussions were the chosen mode of data collection. Eighteen participants with knee OA were interviewed individually, and 19 community health care workers participated in three area specific focus group, providing collateral information about the community and their health related behaviour. The first two individual interviews were used as pilot interviews, therefore the data of the remaining 16 individual interviews were used along with the focus group data for analysis. The transcribed and translated interviews were coded using the coding software Atlast.ti, after which a deductive data analysis approach was followed.

Results

The results showed that the current services offered to individuals with knee OA living in the rural areas of the Western Cape are insufficient in addressing their concerns and managing their symptoms. Various

rehabilitation needs have been identified in these areas of which information and exercise needs were the most prominent. The needs identified could be addressed by a self-management and education programme within these communities. However, contextual barriers and facilitators have been identified as possible aspects which could influence the implementation of a self-management and education programme. Personal factors such as ownership, compliance and social isolation as well as environmental factors such as the community attitudes, continuity of care and available transport could have an impact on the uptake and success of a self-management and education programme.

Conclusion

This study found that when compared to current clinical practice guidelines, the services offered to people living with knee OA are not sufficient and that there is a need for education and exercise. A self-management programme are the ideal intervention to address the needs of the people living with knee OA in rural areas of the Western Cape. However, this study identified certain contextual factors that has to be considered when planning and implementing such a programme, and a feasibility study should be considered to ascertain the strategy for implementation in these areas.

KEYWORDS: KNEE, OSTEOARTHRITIS, SELF-MANAGEMENT, RURAL, CONTEXTUAL, PERSONAL, ENVIRONMENTAL, NEEDS, SERVICES

Opsomming

Agtergrond

Muskuloskeletale (MS) kondisies is 'n globale gesondheids bekommernis en die effek van MS verwante gestremdheid is verhoog in landelike gebiede waar lede van die gemeenskap deur hul omgewing en sosiale omstandighede geaffekteer word. Die implementering van 'n self-hantering en opvoedingsprogram kan die gesondheidsuitkomstes van individue in hierdie omgewings verbeter. Die aanbevelings in die huidige bewysgesteunde kliniese praktyk riglyne het egter 'n tekort aan konteks spesifieke inligting. Om die konteks te verstaan kan dit die opname van hierdie riglyne verbeter en dus die pasiëntsorg en gesondheiduitkomstes van hierdie individue verbeter.

Doel

Die doel van hierdie studie was om die kontekstuele faktore te beskryf wat 'n invloed kan hê op die implementering van 'n self-hantering en opvoedingsprogram vir mense met knie osteoarthritis (OA) wat in landelike gebiede van die Weskaap, Suid Afrika woon.

Metode

'n Beskrywende en verkennende kwalitatiewe navorsingsmetode is gevolg met 'n fenomenologiese aanslag om hierdie studie uit te voer. In diepte gedeeltelik gestruktureerde individuele onderhoude asook fokus groep onderhoude is gekies as die metode van data insameling. Onderhoude is gevoer met 18 deelnemers wat knie OA het en 19 gemeenskap gesondheidswerkers, wat kolaterale inligting oor die gemeenskap en hul gesondheidsverwante gedrag kon verskaf. Die eerste twee individuele onderhoude is gebruik as toets onderhoude, dus is die oorblywende 16 individuele onderhoude saam met die fokus groep gesprekke gebruik vir analise. Die transkripsies is vertaal en gekodier met die Atlas.ti koderings sagteware, waarna 'n deduktiewe data analise gevolg is.

Resultate

Die resultate toon dat die huidige dienslewering aan individue met knie OA wat in landelike gebiede van die Weskaap woon, nie voldoende is om hul kommer aan te spreek of hul simptome te hanteer nie. Verskeie rehabilitasie behoeftes is geïdentifiseer in hierdie areas, en die grootste tekortkoming was korrekte inligting en oefen programme. Hierdie behoeftes kan aangespreek word deur 'n self-hantering en opvoedingsprogram in hierdie gemeenskappe. Kontekstuele hindernisse en fasiliterende aspekte wat 'n invloed kan hê op die implementering van 'n self-hantering en opvoedingsprogram is egter geïdentifiseer. Persoonlike faktore soos eienaarskap, die volvoering en sosiale isolasie sowel as omgewingsfaktore soos die gemeenskap se instelling, kontinuïteit van sorg asook vervoer kan 'n impak hê op die opname en sukses van 'n self-hantering en opvoedingsprogram.

Gevolgtrekking

Hierdie studie het gevind dat in vergelyking met die huidige kliniese praktyk riglyne, die dienste wat aan mense met knie OA gebied word nie voldoende is nie, en daar steeds 'n behoefte is aan opvoeding en oefening. 'n Self-hanterings program is die ideale ingryping om die behoeftes van mense met knie OA wat in landelike gebiede van die Weskaap woon, aan te spreek. Die studie het egter ook kontekstuele faktore geïdentifiseer wat in ag geneem sal moet word tydens die beplanning en implementering van so 'n program. Dus word 'n haalbaarheidsstudie voorgestel om 'n strategie te ontwikkel vir die implementering van so 'n program in hierdie areas.

SLEUTELWOORDE: KNIE, OSTEOARTRITIS, SELF-HANTERING, LANDELIKE, KONTEKSTUELE, PERSOONLIK, OMGEWING, BEHOEFTE, DIENSTE

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List of Acronyms and Abbreviations

ADL's	Activities of Daily Living
CHC	Community Health Centre
CPG	Clinical Practice Guideline
CBR	Community-based rehabilitation
DoH	Department of Health
EBP	Evidence-based practice
HIV	Human Immunodeficiency Virus
HREC	Health Research Ethics Committee
ICF	International Classification of Functioning, Disability and Health
MDT	Multidisciplinary team
MSK	Musculoskeletal
NCD	Non-Communicable Diseases
NICE	National Institute for Health and Excellence
OA	Osteoarthritis
PHC	Primary health care
PI	Primary Investigator
OARSI	Osteoarthritis Research Society International
QoL	Quality of Life
SA	South Africa
SU	Stellenbosch University
TIDieR	Template for Intervention Description and Replication
WHO	World Health Organisation

Definition of terms

Clinical practice guideline: Evidence-based clinical practice guidelines represent a systematic approach to translating the best available research evidence into clear statements regarding treatments for people with various health conditions (Hollon, Areán, Craske, Crawford, Kivlahan, Magnavita *et al.*, 2014).

Community-based rehabilitation: CBR is a strategy within general community development for the rehabilitation, equalisation of opportunities and social inclusion of people with disabilities (World Health Organization, 2010).

Community health care workers: Community health workers should be members of the communities where they work, should be selected by the communities, should be answerable to the communities for their activities, should be supported by the health system but not necessarily a part of its organization, and have shorter training than professional workers (World Health Organization, 2007).

Contextual factors: Represent the background to an individual's life and include environmental factors (age, gender, race, educational background, experiences, personality, character style, lifestyle, upbringing and coping styles) (Department of Health, 2015).

Evidence-based practice: The conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients (Sackett, 1997).

Environmental Factors: The physical, social and attitudinal environment in which people live and conduct their lives. These are either barriers to or facilitators of the person's functioning. (World Health Organization, 2002) .

Functioning: Is an umbrella term used to describe body functions, body structures, activities and participation. It denotes the positive aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors) (Department of Health, 2015).

Life situation: A complex of factors that describe life circumstances. These include formal education and amount of schooling, training and postsecondary education, profession and income, ownership of cultural items, cultural habits, residence and ownership, liquidity, and creditworthiness (Grotkamp, Cibis, Nüchtern, von Mittelstaedt & Seger, 2012).

Multi-disciplinary team: A team of professionals including representatives of different disciplines who coordinate the contributions of each profession, which are not considered to overlap, in order to improve patient care (Medical Dictionary, 2012).

Musculoskeletal disorders: Musculoskeletal conditions are typically characterised by pain (often persistent pain) and limitations in mobility, dexterity and functional ability, reducing people's ability to work and participate in social roles with associated impacts on mental wellbeing, and at a broader level impacts on the prosperity of communities. The most common and disabling musculoskeletal conditions are osteoarthritis, back and neck pain, fractures associated with bone fragility, injuries and systemic inflammatory conditions such as rheumatoid arthritis (World Health Organization, 2018).

Peer leader: The provision of emotional, appraisal and informational assistance by a created social network member who possesses experiential knowledge of a specific behaviour or stressor and similar characteristics as the target population (Dennis, 2003).

Peri-urban: Areas occupied by informal settlements, consisting of multiple cultures living in conditions that are of inferior standard, on the boundary of urban areas (Republic of South Africa, 2011).

Personal Factors: The particular background of an individual's life and living, including features of the individual that are not part of a health condition or health states, and which can impact functioning positively or negatively (Grotkamp *et al.*, 2012).

Physical Disability: A physical disability is a limitation on a person's physical functioning, mobility, activities of daily living, dexterity or stamina. This has an impact on self-care, function and vocational ability (Department of Health, 2015).

Primary health care: A basic level of health care that includes programmes directed as the promotion of health, early diagnosis of disease or disability, and prevention of disease. Primary health care is provided in an ambulatory facility to limited numbers of people, often those living in a particular geographical area (Medical Dictionary, 2009).

Rehabilitation: The term *rehabilitation* is a goal-directed process to reduce the impact of disability and facilitate full participation in society by enabling people with disability (PwD) to reach optimum mental, physical, sensory and/or social functional levels at various times in their lifespan (Department of Health, 2015).

Rural: Sparsely populated areas in which people farm or depend on natural resources, including villages and small towns that are dispersed through these areas. (Republic of South Africa, 2011).

Self-management: Active participation by a patient in his or her own health care decisions and intervention. With the education and guidance of professional caregivers, the patient promotes his or her own optimal health or recovery (Medical Dictionary, 2009).

Urban: The 'built environment' that includes all non-vegetative, human-constructed elements, such as roads, buildings, runways with public transport available (Republic of South Africa 2011).

Chapter 1

Introduction

1.1. Background and introduction

In the global health care context, musculoskeletal (MSK) related disorders are remarkably prevalent, and are currently the second largest contributor to physical disability (March, Smith, Hoy, Cross, Sanchez-Riera, Blyth *et al*, 2014). Most MSK disorders cause some form of functional limitation within the individual such as difficulty walking, sitting, standing, climbing stairs and fine motor function, which affects various aspects of their lives. Functional activities such as walking, kneeling and stairclimbing is essential for community participation and even basic survival, and impairments in functional mobility due to physical disability have dire consequences for the well-being of these individuals. This is concerning as sixty nine percent of individuals live in rural and peri-urban settings (Statistics South Africa, 2012) who are dependent on their mobility to participate in activities of daily living (ADL's), fulfilling occupational duties and to access health care. Living conditions and available opportunities vary greatly among people in the urban (cities and suburbs) areas compared to peri-urban (towns) and rural (villages of former homeland) settings (Republic of South Africa, 2011). In rural and peri-urban areas, people often need to walk to perform their daily chores (get water, do laundry, go to the local shop), access transportation to go to work, perform various community duties and attend the local clinics for their health care needs. The physical disability and mental stressors caused by MSK disorders therefore often affects the role of the individual in their domestic, occupational, social and community life (Litwic, Edwards, Dennison & Cooper, 2013). In addition, these individuals are dependent on the primary health care (PHC) system to provide them with rehabilitation for their disability, which assists them in maintaining/ re-gaining functionality (Major-Helsloot, Crous, Grimmer-Somers & Louw, 2014). However, for rehabilitation at PHC level to be optimal, the use of evidence-based practice (EBP) within these settings are essential to assist the population that are most dependant on their mobility. Therefore the application of a clinical practice guideline for functionally restrictive disorders, such as MSK related disorders, within these settings are indicated (Forland, Rohwer, Klatser, Boer & Mayanja-Kizza, 2013). Nevertheless, the needs and circumstances within peri-urban and rural areas vary greatly from those seen within urban settings, where the majority of evidence-

based research is performed. This may have implications for the implementation of clinical practice guidelines as currently presented in the literature, within rural areas.

1.2. Significance of this study

Currently, bountiful research is being produced and a movement towards evidence-based practice and clinical practice guidelines are encouraged. However, in the rural primary health care settings one clinician is treating a wide variety of conditions, and often needs to consult research and evidence to ensure that correct treatment is provided for conditions they have less experience in treating. Considering that osteoarthritis are currently the second largest contributor to physical disability in the world (March *et al.*, 2014), there are a need for applying evidence-based practice to these conditions. In addition an estimated 80% of the total burden of osteoarthritis (OA) is attributed to OA of the knee. However, as found by Heyns (2018), clinical practice guidelines on knee osteoarthritis lacked detailed description for application in practice, and are not considering the contextual factors that could influence the implementation of these recommendations. The clinicians are therefore unable to provide care based on the current best evidence, and patients are unable to access the best care. This study forms part of a larger project that is aiming to develop a contextualised programme/ cell phone application that can be readily used by service providers as well as service users. Therefore OA of the knee was chosen as the vehicle to determine the process for developing a contextualised and user friendly product (Wallace, Worthington, Felson, Jurmain, Wren, Maijanen, Woods & Lieberman, 2017)

The first part of the process was to evaluate the interventions as currently described by the knee OA clinical practice guidelines (CPG's) using the TiDieR. The outcome of this study demonstrated that even though abundant research is available on the use of self-management and education of knee OA, the randomised controlled trials (RCT's) used in the compilation of the knee OA CPGs were not clinically reproducible and could not be used as it is currently published and lacked contextual information (Heyns, 2018).

This study formed the second part of the process and was used to identify the contextual barriers and facilitators which could influence the implementation of a self-management programme within the rural areas of the Western Cape. Through identifying the contextual factors for implementation, the knowledge gained could be used to adopt current CPG's for implementation within this specific context, and therefore assist in the uptake of the best evidence interventions within these communities (Ernstzen, Louw & Hillier, 2017). This could improve patient outcomes such as empowerment to improve health related quality of life and to return

to work, as well as affect health care system outcomes by improving the efficacy and safety of patient care and reducing long term costs involved in the management of joint disorders.

1.3. Research question

What are the contextual factors that could influence the implementation of evidence-based self-management and education programs for people with knee OA living in rural settings of the Western Cape?

1.4. Aim of this study

The aim of this particular study was to describe the contextual factors that could influence the implementation of a self-management and education programme for people with knee OA living in the rural settings of the Western Cape.

1.5. Objectives

The primary objectives of this study was to:

- I. Determine the current rehabilitation practices offered to patients with knee OA (from the view of the patient) attending PHC facilities in the rural settings of the Western Cape.
- II. Identify the rehabilitation needs of the people living with knee OA within the rural settings of the Western Cape.
- III. Investigate the contextual barriers (personal and environmental), that could influence the patient's participation in a self-management and education programme, from the view of the patient living with knee OA and their community health care workers.
- IV. Investigate the contextual facilitators (personal and environmental), that could influence the patient's participation in a self-management and education programme, from the view of the patient living with knee OA and their community health care workers.

1.6. Rationale

The information and knowledge from this study could assist researchers, health care providers and policy makers to:

- I. Gain an understanding of the current rehabilitation strategies in rural PHC for knee OA.
- II. Gain an understanding of the current rehabilitation needs of people in rural areas living with knee OA.
- III. Gain an understanding of the barriers and facilitators for implementing a self-management and education programme in rural Western Cape for people living with knee OA.
- IV. Form a baseline for future research in contextualisation of clinical guidelines, and their implementation in other rural areas of South Africa and recognise the importance of contextual information in clinical guideline implementation.
- V. Assist in the development of a user friendly, contextualised clinical practice guideline for self-management of knee OA.

1.7. Study setting

The setting of this study was randomly selected rural areas of the Western Cape.

1.8. Study methods

A descriptive and exploratory qualitative research method with a phenomenological approach, as described by Creswell, Hanson, Clark Plano and Morales (2007), was used to conduct this study. In-depth semi-structured individual interviews and focus group discussions were used as a mode of data collection (Mays & Pope, 2006).

1.9. Structure of this thesis

This thesis will be presented as follows

Chapter 1: This is the *introductory* chapter of the thesis providing the aims and objectives of the study along with an overview of the methods used.

Chapter 2: This chapter focusses on the *literature* supporting the rationale for the study.

Chapter 3: In this chapter, the *methodology* used to perform the study will be discussed in depth.

Chapter 4: The *results* of the study are presented in this chapter.

Chapter 5: A *discussion* of the findings of the study in accordance with literature to support or contrast the findings are presented in this chapter.

Chapter 6: The *conclusion* of the study is presented in the last chapter. The limitations and recommendations of the study will also be outlined in this chapter.

Chapter 2

Literature overview

2.1. Musculoskeletal disorders

2.1.1. Global burden of musculoskeletal disorders

Musculoskeletal (MSK) disorders are currently under the microscope for its impact on the global burden of disease. These disorders have been dubbed the second largest contributor to physical disability in the world (March *et al.*, 2014). MSK disorders is the umbrella term used for spinal pain, osteoarthritis (OA), rheumatoid arthritis (RA), gout and bone mineral density problems, which are all disorders known for causing functional limitations within the individual (Weigl, Cieza, Cantista & Stucki, 2007). However, the calculated increase in MSK related disabilities was 45% from 1990-2010, with a high proportional increase seen in sub-Saharan Africa (March *et al.*, 2014). Although MSK disorders affects people of both developed and developing countries, the emphasis has been placed on middle and low income countries due to the greater increase in the older to younger people ratio that is estimated to occur in developing countries in the next few years (March *et al.*, 2014). Considering the increasing rate of prevalence as well as the ageing population, MSK disorders will become one of the greatest global health concerns within the next few decades (Brooks, 2006; March *et al.*, 2014).

2.1.2. Musculoskeletal related disability

A primary concern is that with an increase in the rate of MSK disorder prevalence, the rate of physical disabilities increase due to the long term effect of these disorders (March *et al.*, 2014). Most MSK disorders result in functional impairments that are associated with pain, decreased range of motion (ROM) in the affected areas, muscle weakness, inflammation (acute, chronic or flare-up stages) and effusion, of which pain is the main contributor to functional incapacity (Woolf & Pfleger, 2003). The individual often experiences difficulty in walking, standing or sitting for long periods of time, stair climbing, fine motor movements and endurance, impacting various aspects of their daily life. Areas of life affected by these functional impairments are commonly

related to their occupational duties (including manual labourers as well as office workers), ability to travel (especially when using public transport), domestic chores and community involvement (Woolf & Pfleger, 2003). This in turn, has an impact on their ability to generate an income, take care of their families (on a physical and financial level) as well as participate in community and social activities, frequently leading to psychological distress and impacting their general quality of their life (QoL) (Weigl *et al.*, 2007).

2.1.3. Musculoskeletal related disability and rehabilitation

As defined by the World Health Organisation (WHO), rehabilitation is *“a set of interventions designed to optimize functioning and reduce disability in individuals with health conditions in interaction with their environment”* (World Health Organization, 2017). Essentially, rehabilitation aims to restore the ability of an individual to participate in their daily lives by reducing activity limitations, restoring function and improving their QoL (Weigl *et al.*, 2007). Rehabilitation typically consists of exercise, education, manual therapy, dietary changes, electrotherapy, pharmacological treatment and assistive devices which is all essential for the management of people with MSK disorders (Meneses, Goode, Nelson, Lin, Jordan, Allen *et al.*, 2016). Not only does rehabilitation prevent/ reduce deformity and functional impairment, it also delays the progression of most MSK related disorders and should always be considered as the first treatment option as it is a non-invasive alternative to surgery (Nelson, Allen, Golightly, Goode & Jordan, 2014).

2.1.4. Rehabilitation and Primary Health Care (PHC)

Primary health care (PHC) is a term used to describe the first line of health care contact for an individual in an organized health care system (Kautzky & Tollman, n.d.; WHO, 2003). This service is typically located closest to where the individual lives and is a low cost basic service that addresses most of the non-specialized needs of the people in the area. Services offered at the PHC facilities are typically family medicine, chronic care, maternity care, rehabilitation services, pharmacology and dentistry (Republic of South Africa, 2017). Considering that PHC is the first level of contact for individuals and is ideally close to the person, the PHC system provides the ultimate platform for optimal management of physical disability and musculoskeletal disorders as it incorporates health promotion, prevention and curative care. (Major-Helsloot *et al.*, 2014; Sherry, 2015). However, until recently physical disability and rehabilitation was not seen as an essential component of health care, and has been poorly defined in the policies and strategies of the South African health care system in the past (Sherry, 2015). This late recognition of the importance of rehabilitation has led

to the absence of planning and resource allocation by the government for rehabilitation within the public sector (Republic of South Africa, 2015; Sherry, 2015). Rehabilitation services are ideally provided by a multi-disciplinary team (MDT), consisting of a doctor, physiotherapist, occupational therapist, social worker, psychologist and dietician who all have their specific role in assisting the patient (Schwarz, Neuderth, Gutenbrunner & Bethge, 2015). However, involving all the members of the MDT is a time consuming and costly intervention and often there are not enough clinicians for the amount of patients in a certain geographical area, especially rural settlements (Carvalho, Bettger & Goode, 2017). Therefore, more often than not a patient is only seen by one or two of the above mentioned health care professionals, especially in the PHC context (Rhoda, 2016). Resource planning should address the urgent need for human resources, assistive devices and rehabilitation equipment within the public sector, to improve access to rehabilitation and functional outcomes for people dependant on PHC (Kautzky & Tollman, n.d.; Sherry, 2015).

However, a promising recent shift in policy through The Framework and Strategy for Disability and Rehabilitation services in South Africa now recognise that rehabilitation is the link between medical treatment and the functional productivity of an individual within their environment (Department of Health, 2015) . This integrated functional improvement could be achieved by using the Community-based Rehabilitation (CBR) approach as described by the World Health Organisation (WHO, 2010). The CBR approach will help to ensure that individuals receive accessible, and affordable health care, empowering them to achieve their full potential within their context. The role of the community health care workers (CHCW) are therefore becoming even more prominent in this approach, as they are the link between the community and the clinic. They play a crucial role in identifying the health care needs of the community, promoting health and wellness and providing social support to members of the South African communities (Thomson, 2016). They assist in reducing the patient load at the clinic, providing education to members of the community and to assist in early detection of various health related conditions.

2.1.5. PHC in South Africa: focussing on rural areas

South Africa is a country rich with diversity and culture and is host to 51.9 million residents, all living within the nine provinces of the country. However, South Africa remains one of the most unequal countries in the world (Ataguba, Day & McIntyre, 2015). Living conditions and available opportunities vary greatly among people in the urban (cities and suburbs) areas compared to peri-urban (towns) and rural (villages of former homeland) settings. Sixty nine percent of individuals live in rural and peri-urban settings (Statistics South Africa, 2012)

who are dependent on their mobility to participate in activities of daily living (ADL's), fulfilling occupational duties and to access health care. Currently, health care is provided in the public care sector by 30% of the health care providers in the country, to more than 40 million people, with a majority of the care provided at the PHC facilities (Dookie & Singh, 2012; Maillacheruvu & Mcduff, 2014). However, it is a well-known frustration that there are long waiting times at the PHC facilities and follow up appointments are not frequent enough for most of the rehabilitation needs of individuals, which exacerbates poor adherence to medical care and rehabilitation (Major-Helsloot *et al.*, 2014; Rhoda, 2016). Furthermore, people living with musculoskeletal disorders and physical disabilities seek medical care more often than the average healthy person (WHO, 2016). Unfortunately, as the disease progresses their health care needs also increases, placing a significant burden on healthcare systems (Litwic *et al.*, 2013). Considering the impact of physical disabilities on the mobility and functioning of the individual, the consequences of experiencing difficulties in walking, upper limb functioning and various functions of daily living is amplified in a rural setting (Vergunst, Swartz, Mji, MacLachlan & Mannan, 2015).

Rural settings, as defined by the Department of National Treasury (2011), are sparsely populated villages and small towns that are dependent on natural resources. These communities are often troubled by low socioeconomic circumstances which are augmented by the lack of occupational opportunities, poor infrastructure such as water and sanitation, poor public transport systems and inadequate public health care services (Neves & du Toit, 2013). Individuals often face physically demanding domestic and occupational chores and have to walk far distances to access health care or public transport services (Neves & du Toit, 2013). In addition, occupational opportunities are scarce and due to the historical tendency of low educational levels amongst people living in rural areas, they often work on agricultural farms in their surrounding area (Aquino, Falcon, Neves, Rodrigues & Sendín, 2011). These jobs are usually physically demanding in nature, and the effect of disability due to a MSK disorder is detrimental to their ability to fulfil their occupational duties. The competitive nature of the job market would then result in dismissal on grounds of incapacity, leading to unemployment, putting them at risk of becoming part of the cycle of poverty (Department of Health, 2015; Sherry, 2015).

Additionally, if the MSK disorder is progressive in nature, disease progression would gradually affect their functionality in their daily lives (Woolf & Pfleger, 2003). Domestic tasks in and around the house are often complicated by the structural inadequacies of rural areas. Informal houses with no running water and electricity inside the house is a frequent occurrence in these areas, worsened by the lavatory amenities and communal

taps that are often situated far from their homes (Geere, Hunter & Jagals, 2010, Statistics South Africa, 2017). This is even further complicated by the terrain in and around the community, which is often in poor condition especially in rainy seasons which creates a dangerous environment for individuals with balance and walking difficulties (Vergunst *et al.*, 2015). However, according to McLaren, (2013), twenty six percent of individuals attending PHC facilities live further than 5 km away. This is concerning as people with physical disabilities are usually unable to walk the required distances to access health care and are dependent on transport opportunities from neighbours and family, often at great financial expense to the patient (Vergunst *et al.*, 2015). Community-based rehabilitation targeting physical disability is therefore advocated at community and PHC levels within rural areas to ensure higher functioning among community dwellers to perform their daily tasks, travel to where they need to be and to restore their roles and dignity within society.

However, the human resource constraints has affected the delivery of rehabilitation services and alternative options to rehabilitation service delivery has been explored. These options includes a call for educating and employing mid-level rehabilitation workers and internet support services delivered through smartphone applications and other telecommunication (Department of Health, 2015; Sherry, 2015; Carvalho *et al.*, 2017). Therefore, to ensure that the rehabilitation services offered for MSK disorders is suitable and consistent in nature, the use of evidence-based practice in the form of clinical practice guidelines, should be encouraged.

2.1.6. PHC and evidence-based practice

“Evidence-based decision-making has become an indispensable practice universally because of its role in ensuring efficient management of population, economic and social affairs” (Lehohla, 2011). Evidence-based practice (EBP) is defined as the use of current best available evidence from research in the decision making about health care for individuals (Sackett, 1997). According to Forland (2013), embracing EBP to ensure beneficial rehabilitation at PHC level is therefore essential in the areas most in need of health care, to ensure that sparse resources are used wisely, time is spend efficiently and the best patient care is provided at each opportunity (Kredo, Machingaidze, Louw, Young & Grimmer, 2016). Nevertheless, the uptake of standardised rehabilitation practices at primary care level is currently hampered by the poor quality of clinical practice guidelines (CPG's) as well as the lack of transparency and contextual factors (Ernstzen, Louw & Hillier, 2017; Machingaidze, Zani, Abrams, Durao, Louw, Kredo *et al.*, 2017).

In addition, the PHC system is typically burdened by HIV/AIDS, TB and other prioritized conditions, which leads to less resources available for rehabilitation at this level (Govender, Fried, Birch, Chimbindi & Cleary, 2015). The rehabilitation specialists at primary health care (PHC) level are generally understaffed (with regards to time, resources and accessibility) and have to tend to a variety of rehabilitation needs within the large patient population that are present in these areas.

Even though an attempt has been made to address the human resource constraints of the system with the mandatory community service year upon completion of health related degrees, there are still a lack of rehabilitation professionals in public health care (Department of Health, 2015; Ned, Cloete & Mji, 2017). Thus to ensure that the time spent with the patient is done optimally and that the patient receives a well-structured self-management programme for maintaining their chronic condition at home, therapy should be based on the best scientific evidence of efficacy.

2.1.7. The practical use of evidence in practice: Barriers/ implications

With the new era of evidence-based practice and the movement towards clinical practice guidelines (CPG) as a result, more and more studies are collated in an effort to produce a one stop guide for clinicians in the treatment of specific conditions (Grimshaw, Freemantle, Wallace, Russell, Hurwitz, Watt *et al.*, 1995; Hollon *et al.*, 2014). However, even if the clinician has access to the current evidence provided in clinical practice guidelines (CPGs), they are unable to interpret and implement it accordingly. The clinical guidelines are usually not explicit enough and lack clear procedural details and user friendly algorithms, hindering direct translation into practice (Meneses *et al.*, 2016). In addition, the contextual factors which comprise environmental, social and cultural background, are rarely taken into account when developing and implementing clinical guidelines, thus the CPG is not tailored for the individual patient within his specific context (Mercuri, Sherbino, Sedran, Frank, Gafni & Norman, 2015; Ernstzen *et al.*, 2017). Considering the three aspects of evidence-based practice which includes the clinical expertise of the clinician, the research evidence as well as the patient's circumstances and values (figure 2:1), the latter is often omitted in the clinical practice guidelines (Hoffmann, Montori & Del Mar, 2014).

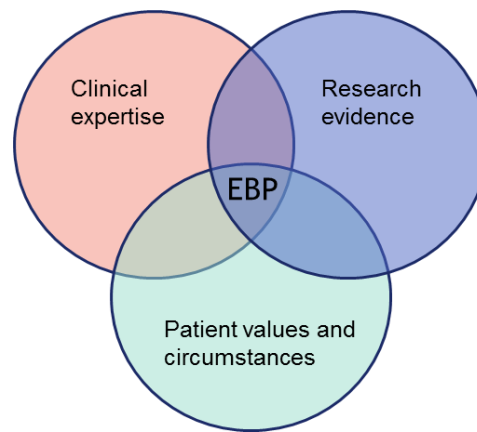


Figure 2:1 Components of evidence-based practice (Library Resource Guide, n.d.)

2.2. Bridging the gap

A different strategy is thus required for the optimal uptake of evidence based rehabilitation for MSK related disabilities at community level to assist the clinicians in clinical decision making and to provide the best evidence-based care to patients at their fingertips. One such strategy could include the use of flipcharts (also known as a quick reference guide) or a cell phone application which will allow clinicians to make clinical decisions rapidly and efficiently in areas they are less experienced in. This will ensure that the patient receives the best possible care at the few occasions they are able to consult with the clinician. In addition, this information could also be used by the patients themselves to maintain their condition at home in between long follow up periods. The patient is a key stakeholder in the management of their own health and should be empowered by having access to good quality information and self-management tools (Stenberg, Haaland-Øverby, Fredriksen, Westermann & Kvisvik, 2016). In order for recommended interventions in CPGs to be reproducible within clinical practice at community level and be presented in a user friendly manner, a number of interim steps are required to ensure that the end user can successfully implement the interventions as suggested by the CPG within their context (Ernstzen *et al.*, 2017). Since the logistical process for developing a contextualized and user friendly product (such as a flipchart or cellular phone application) for use by clinicians and patients is not clear, a vehicle topic has been chosen to establish the procedure and identify all the possible obstacles in achieving such an outcome. Being one of the largest contributors to MSK related functional disability and its prevalence among the ageing communities (Wallace, Worthington, Felson, Jurmain, Wren, Maijanen *et al.*, 2017), osteoarthritis (OA) of the knee was chosen as the vehicle topic.

2.3. Osteoarthritis as the vehicle

OA has been dubbed the leading cause of chronic joint disorders in both developed and developing countries, with an increase in prevalence that doubled over the past 50 years (Wallace *et al.*, 2017). An estimated 80% of the total burden of OA is attributed to OA of the knee, therefore the focus of current research is placed on developing an understanding of knee OA and improving the treatment strategies (Wallace *et al.*, 2017). Due to the increasing prevalence of OA, the research and information dissemination has also increased, leading to cumulative amounts of tested programmes and opinions for the management of this chronic condition. In 2013, a systematic review by Jaramillo *et al.* concluded that prevention strategies and self-management interventions should be top priorities for research and reviews within the field of OA. Therefore, the focus for this project was placed on self-management and education as an intervention, due to the promising results shown in previous studies when used as a long term intervention for knee OA (Kruger-Jakins, Saw, Edries & Parker, 2016; Stenberg *et al.*, 2016; Angwenyi, Aantjes, Kajumi, De Man, Criel & Bunders-Aelen, 2018). Self-management is defined as a skill needed by the individual for the lifelong task of controlling chronic diseases and is the engagement of daily behavioural, emotional and medical decision making (management) on the part of the individual (Lorig & Holman, 2003). Self-management is therefore an efficient rehabilitation plan for the long term management of OA of the knee (Devos-Comby & Cronan, 2006). The following section is a summary of the current information available on OA of the knee and will be followed by a description of self-management and education as a method of intervention.

2.3.1. Definition of OA

Osteoarthritis (OA) is currently seen as a chronic progressive joint disorder which leads to the degeneration of the articular cartilage, synovial inflammation, changes in the subchondral bone as well as meniscus loss which eventually leads to functional disability and a decline in quality of life (QoL) for people aged 45 years and older (WHO, 2013; Favero, Ramonda, Goldring, Goldring & Punzi, 2015). OA commonly affects the joint of the hips, knees and hands and are more frequently seen in females than in males with a ratio of 2:1 (Woolf & Pfleger, 2003). OA has however been labelled a heterogeneous condition due to the diversity in its clinical presentation, the uncertainty of the biological initiation of the disorder and the variation in response to treatment (Driban, Sittler, Barbe & Balasubramanian, 2010). Due to the progression of the disorder over decades, which results in a decline within the affected joints as well as pain and dysfunction, patients often only seek medical treatment

during the later stages of OA. At this stage a symptomatic diagnosis is made based on stiffness in the joint, functional limitations, risk factors (BMI, age, gender, family history, occupation and previous injuries to the joint) and radiographical findings of deterioration in cartilage and new bone formation. It has been contested by some medical professionals that a patient can be completely asymptomatic and have clear radiological deterioration, for which they are diagnosed with asymptomatic OA (Dean, 2012). Therefore the Osteoarthritis Research Society International (OARSI) has following preferred definition:

“Osteoarthritis is a disorder involving movable joints characterized by cell stress and extracellular matrix degradation initiated by micro- and macro-injury that activates maladaptive repair responses including pro-inflammatory pathways of innate immunity. The disease manifests first as a molecular derangement (abnormal joint tissue metabolism) followed by anatomic, and/or physiologic derangements (characterized by cartilage degradation, bone remodelling, osteophyte formation, joint inflammation and loss of normal joint function), that can culminate in illness” (OARSI, 2015).

2.3.2. Impact of knee OA on function

Considering the average age of the person with OA (especially OA of the knee), the majority of affected people in South Africa are categorised in the economically active population, as the average age for working is between 15 and 65 (Statistics South Africa, 2018). At this stage in their life, individuals are still active participants within their family, occupational, social and community environments, and being functionally affected by OA of the knee could have a detrimental effect on their participation in everyday life. However, the younger population of OA affected individuals (20 -55 years of age) are even more distinctly affected in their quality of life (Ackerman, Kemp, Crossley, Culvenor & Hinman, 2017), considering their level of physical activity, young family life and the start of their career which could be influenced by the functional deficits of OA. Psychological distress in these adults where measured to be four times higher than in their peers and their chances of being removed from the labour force increases by 64% when diagnosed with OA (Ackerman *et al.*, 2017). Figure 2:2 below is a presentation of the effect of hip and knee OA on an individual, according to the international classification of function (ICF) (Ackerman, 2017):

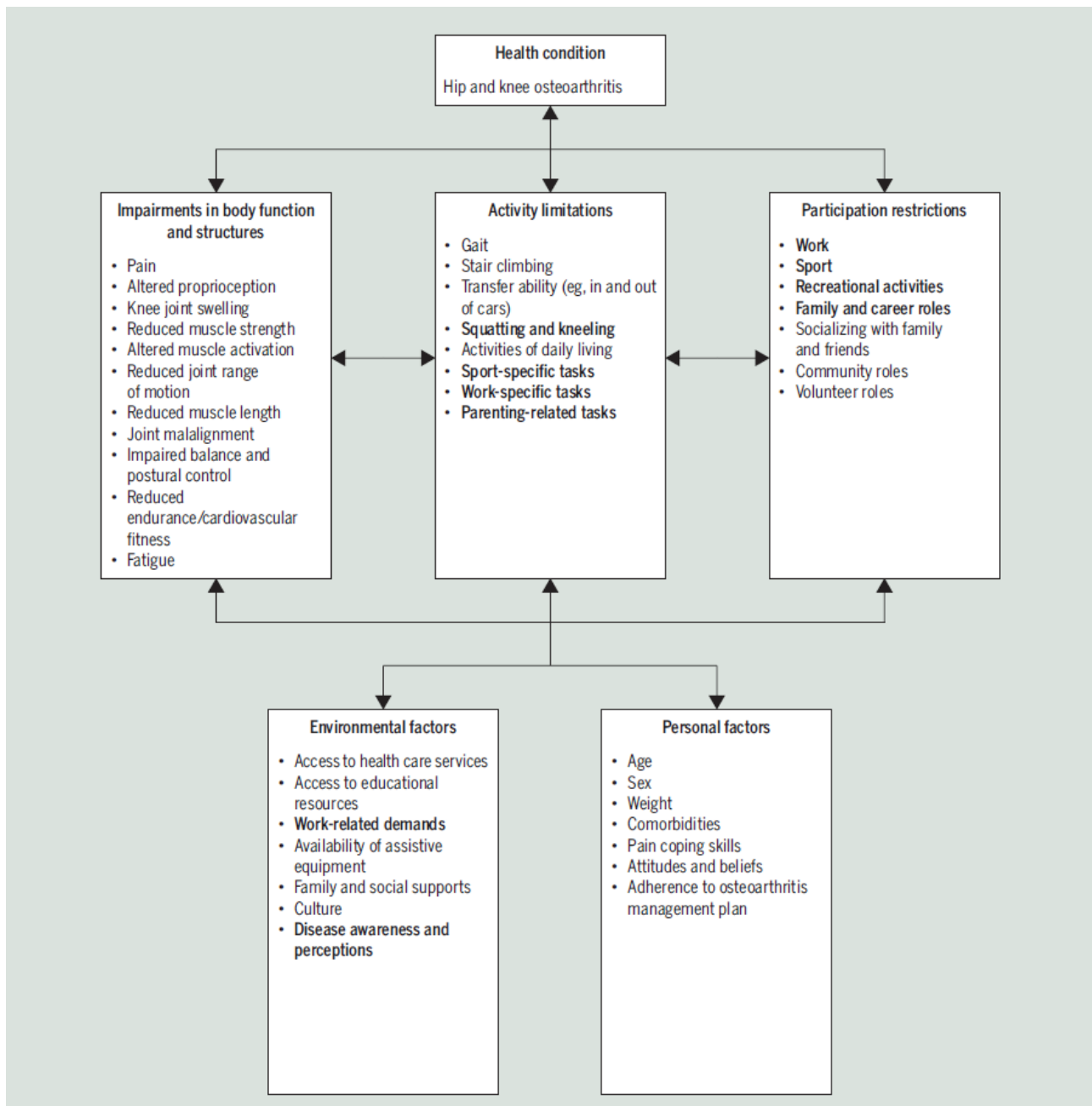


Figure 2:2 ICF framework for the impact of hip and knee OA (Ackerman, 2017)

2.3.3. Current management strategies for knee OA rehabilitation

It is widely known that OA has a high socioeconomic burden on the health systems of the world as well as the individual (Migliore, Scirè, Carmona, Herrero-Beaumont, Bizzi, Branco *et al.*, 2017). The ageing population along with the increase in injuries among the youth is largely attributed to the OA phenomenon and has been estimated to keep increasing over the next few decades (Loeser, 2010; Ackerman *et al.*, 2017). However, no

therapy/ intervention has shown to consistently delay the progression of the disorder (Favero *et al.*, 2015), even though a few management programmes has proven to offer symptomatic relief to the individuals with OA (Driban *et al.*, 2010). Due to the heterogeneity of the disorder, people present with various symptoms and respond differently to interventions, which impedes the use of tailored management programmes. Current management strategies are informed by CPG's of the European League Against Rheumatism (EULAR), the American College of Rheumatology (ACR,) the American Academy of Orthopaedic Surgeons (AAOS), the Osteoarthritis Research Society International (OARSI) and many more (Hochberg, Altman, April, Benkhalti, Guyatt, McGowan *et al.*, 2012; Fernandes, Hagen, Bijlsma, Andreassen, Christensen, Conaghan *et al.*, 2013; Jevsevar, Manner, Bozic, Goldberg, Martin, Cummins *et al.*, 2013; Meneses *et al.*, 2016). Management for knee OA has been divided into pharmacological, non-pharmacological and surgical strategies (Mather, Koenig, Kocher, Dall, Gallo, Scott *et al.*, 2013; Meneses *et al.*, 2016) and the latest recommendations with the level of evidence are presented in table 2:1 below:

Table 2:1 Level of evidence and strength of recommendation for current OA CPGs

Treatment option	Level of Evidence	Quality of Evidence/ Strength of recommendation
Non-pharmacological		
*Weight management	Ia ¹ Ib ²	Good ¹ Moderate ³ Strong ⁴
*Self-management programme and education	Ia ¹ Ib ²	Good ¹ Strong ³ CR ⁴
*Exercise (land based)	Ia ¹ Ia ²	Good ¹ Inconclusive ³
*Exercise (water based)	Ia ¹ Ia ²	Good ¹ Strong ³ Strong ⁴
*Exercise (strength training)	Ia ¹ Ia ²	Good ¹ Strong ³
Occupational assistance/ vocational programme	III ²	
Biomechanical intervention (braces, sleeves, strapping, taping and corrective footwear)	Ia ¹ Ib ²	Fair ¹ Inconclusive/NR ³ CR ⁴
Assistive devices	Ib ¹ Ib ²	Fair ¹ CR ⁴
Pharmacological		
Oral (non-selective NSAID's)	Ia ¹	Good ¹ Strong ³ CR ⁴
Topical NSAID's	Ia ¹	Good ¹ Strong ³ CR ⁴
COX-2 inhibitor and PPI	Ia ¹	Good ¹ Strong ³ CR ⁴

Intra-articular steroids	Ia ¹	Good ¹	Inconclusive ³	CR ⁴
Intermittent acetaminophen/ paracetamol	Ia ¹	Good ¹	Inconclusive ³	CR ⁴
Opioids	Ia ¹	Good ¹	Inconclusive ³	CR ⁴
Surgical				
Arthroscopy and Debridement	Ib ¹	NR ³		
Osteotomy/ Unicompartmental replacement	IIb ¹	Low ³		
TKR	III ¹			

Key:

*Core Treatments

1 - OARSI 2 - EULAR 3 - AAOS 4 - ACR

Level of Evidence		Strength of recommendation AAOS	ACR
Ia	Meta-analysis/ systematic review of RCT's	S - Strong (high quality)	SR (strong – high quality)
Ib	At least one RCT	M - Moderate (moderate quality)	CR (conditional recommendation – absence of high quality evidence)
IIa	At least one controlled trial without randomisation	L - Limited (low quality)	
IIb	At least one type of quasi-experimental study	I - Inconclusive	
III	Descriptive studies	C - Consensus	CNR (conditionally not recommended)
IV	Expert committee reports	NR (Not recommended)	
Quality of evidence (AMSTAR) - Good, Fair, Poor			

There is definite consensus on the use of physical rehabilitation as a treatment option for OA, as it assists in symptom management during the progression of the condition (Kruger-Jakins *et al.*, 2016; Ackerman *et al.*, 2017; Lane, Shidara & Wise, 2017). A physical rehabilitation programme is usually aimed at improving functional ability and decreasing pain, which could lead to an improved quality of life (QoL) (Lamb, Tøye & Barker, 2008; Blagojevic, Jinks & Jeffery, 2010). Due to the slow progression of the condition and the amount of years the patient will spend with symptomatic OA of the knee (for most people it could be decades), the patient should be equipped to manage their condition in their everyday life. Thus self-management and education forms a crucial part of the rehabilitation of people with knee OA and has been listed as one of the core treatment options that should be provided to all patients presenting with knee OA (Conaghan, Dickson & Grant, 2008; Hochberg *et al.*, 2012; Fernandes *et al.*, 2013; Saw, Kruger-Jakins, Edries & Parker, 2016). Self-management has been defined by the Oxford dictionary (2019) as “*management of or by oneself; the taking of responsibility for one's own behaviour and well-being*”.

2.3.4. Self-management and education: content and features for knee OA

People living with symptomatic knee OA frequently experience severe pain and functional limitation, for which non-pharmacological treatment has been the centre point of research over the past decade. In recent studies, the use of a self-management and education programme has delivered mixed results, as Du et al, (2011) found that self-management programs for OA had some effect on pain management after one year. However, a Ottawa review panel found it to only have a short term effect (Egan, Dubouloz, King & Welch, 2011), and a Cochrane review done in 2014 concluded that it is not likely to assist in behavioural or lifestyle changes (Kroon, Lennart, Buchbinder, Osborne, Johnston & Pitt, 2014). However, combining education with exercise has shown to decrease pain, improve the functional mobility and quality of life in patients with late stage OA in the South African PHC setting (Nelson, 2018; Saw *et al.*, 2016; Skou, Pederson, Abbott, Patterson & Barton, 2018). The various aspects of self-management and education programmes that are currently being researched and used are explored below:

2.3.4.1. *Rationale*

In order to promote positive lifestyle changes for people with OA, it has been argued that information regarding the condition itself, symptoms and progression, the importance of exercise and weight loss as well as coping strategies for pain could equip and empower the patient for their everyday life (Coleman, Briffa, Carroll, Inderjeeth, Cook & McQuade, 2012; da Silva, de Melo, do Amaral, Caldas, Pinheiro, Abreu *et al.*, 2015). It also aims to address the concerns of the patient and address their misconceptions, which in turn could assist in behavioural changes (Hurley, Walsh, Mitchell, Nicholas & Patel, 2012). Finally, the development of a standardized self-management and education programme could reduce the use of complex and time consuming interventions, and assist health care professionals to deliver an easily implemented programme and improve adherence from the patients (Ravaud, Flipo, Boutron, Roy, Mahmoudi, Giraudeau *et al.*, 2009). Therefore, the desired outcome of a self-management program would be to empower the patient with coping skills, improve their function and to reduce their pain.

2.3.4.2. *Provider, setting and duration*

According to the WHO (2010), self-management and education are seen as a community-based rehabilitative intervention, delivered to the patients by health care professionals and trained leaders, especially in areas that

are scarce in resources. In some programmes, the intervention is provided by members of the MDT as part of their routine out-patient rehabilitation programmes (Coleman *et al.*, 2012; da Silva *et al.*, 2015). In other cases, the intervention can be delivered by a fellow community member who either has the disorder themselves and has completed the programme or has received training to deliver the content (Lorig, Ritter, Laurent & Fries, 2004). The programme could be delivered at the PHC facility, at a local community centre, church, hall or at home, depending on the type of intervention. The duration of the programme depends on the content and the infrastructure, and is usually set out as weekly/ bi-weekly sessions over 6-10 weeks. Some programmes have homework as part of their intervention and take home exercise programmes to continue with at one's own pace (Hurley *et al.*, 2012).

2.3.4.3. *Mode of delivery*

Various modes of delivery has been explored for the use of a health care intervention, especially for self-management. Some interventions proved to be more beneficial and sustainable than others and has been dependant on resources and personal choice. Individual sessions, telephonic intervention or internet based information sessions are examples of the tools used in various health care settings in an attempt to empower the individual to manage their own condition and to improve their health related quality of life (Kruger-Jakins *et al.*, 2016; Lauckner & Hutchinson, 2016; Dube, Rendall-Mkosi, Van den Broucke, Bergh & Mafutha, 2017, Stanford School of Medicine, 2015). However, it should be considered that not all modes of delivery are feasible in all settings for example the use of mobile phone interventions which were found to be affected by the digital literacy and the infrastructure of settings in South Africa (Watkins, Goudge & Gomez-Olive, 2018). Although a variation in the mode of delivery exists, group interventions have been the choice of intervention for the majority of OA self-management programmes. Group interventions are seen as a manner of providing group support, saving time and being as effective as individual interventions (Hurley, Walsh, Mitchell, Pimm, Patel, Williamson *et al.*, 2007).

2.3.4.4. *Content: Education/ information*

Although education as a stand-alone intervention for OA has not proved to assist in behavioural change, it has been effective for people awaiting surgery and should include topics that are relevant to self-efficacy, psychological wellbeing and improving quality of life (Egan *et al.*, 2011). Clinical guidelines on education vary between current programmes, but they all have certain core aspects in common. Topics covered typically

include a section on the explanation of OA, as it has been frequently found that people with OA lack the basic knowledge on the condition (Migliore *et al.*, 2017). Options for long term management, maintenance and prevention strategies are also discussed with a focus on pain management, exercise and diet (Coleman *et al.*, 2012; Fernandes, Hagen, Bijlsma, Andreassen, Christensen, Conaghan *et al.*, 2013; Kruger-Jakins *et al.*, 2016). The importance of goal setting, coping with depression and isolation as well as relaxation strategies and sleep hygiene as additional areas of focus to equip the individuals with the knowledge and tools to manage their disorder in their everyday life (Kruger-Jakins *et al.*, 2016).

2.3.4.5. *Content: Exercise*

In addition to general education, emphasis is also placed on aerobic and strengthening exercises on a regular basis, to improve their function and reduce pain (da Silva *et al.*, 2015; Thorstensson, Garellick, Rystedt & Dahlberg, 2015; Kruger-Jakins *et al.*, 2016; Skou *et al.*, 2018). Contact sessions typically include group exercises before or after the education section, and individuals are taught to perform the routines at home. Interventions that does not include contact sessions, typically provide the patient with instructional DVDs to watch and follow the exercises at home (Hurley *et al.*, 2007; Ravaud *et al.*, 2009). Exercise routines typically includes cardiovascular exercise on a stationary bike, circuit walking or walking outside, followed by stretching, strength training and functional exercises for balance (da Silva *et al.*, 2015; Skou *et al.*, 2018).

2.3.4.6. *Equipment*

Although interventions vary in the equipment used, most of require minimal equipment, and are in general seen as a low cost intervention for OA of the knee. Some programmes provide the patients with pamphlets and booklets containing information to take home (Heyns, 2018). Workbooks are frequently used in the interactive sessions, encouraging patients to partake in goal setting and pacing. Some programmes provide the patient with a CD containing relaxation music as a pain management strategy, others provide a DVD with home exercises to follow (Kruger-Jakins *et al.*, 2016). Interventions over the telephone have also been investigated and some studies found that it has value for the patient when a medical professional takes the time to follow up with them and address their concerns (Blixen, Bramstedt, Hammel & Tilley, 2004). However, the best evidence is still in favour of physical contact between the health care professional and the patient as opposed telephonic/ home based interventions (Thorstensson, Roos, Petersson & Arvidsson, 2006; Lane *et al.*, 2017).

2.3.5. Self-management and education implementation challenges in SA

Contextual factors are defined by the ICF as physical and environmental factors. The environment constitute of the *“the physical, social and attitudinal environment in which people live and conduct their lives”* and considers factors such as structural environment, social environment (community, neighbors and family), occupational variances, health care services and climate (WHO, 2003). In addition, personal factors are those related to the person themselves factors such as age, gender, race, illness, mental and cognitive abilities, attitudes and behavior and many more that influences the individual (Grotkamp *et al.*, 2012). Considering the South African PHC context and the shortage of resource allocation for rehabilitation, allied health care professionals are overwhelmed by the amount of patients they need to treat (Rhoda, 2016). However, the lack of man power to deliver self-management and education programmes in SA are just one of the challenges faced when considering the implementation of such a programme, especially within the rural context (Rhoda, 2016). Kruger-Jakins *et al.*, (2016) successfully implemented a self-management and education programme at a tertiary hospital in South Africa, which has shown to significantly decrease pain levels and improve function in the short term in adults with late stage OA awaiting surgery. Nevertheless, the rural settings of South Africa are vastly different than the urban setting surrounding the tertiary hospitals where specialized care is available in the form of a multidisciplinary team and specialist doctors (Department of Health, 2002). In these rural settings, patients might not have access to the required services or infrastructure and factors such as illiteracy and adherence could be a barrier to the implementation of a self-management programme in rural areas (Spaull, 2013; Dube *et al.*, 2017). This study will consider the patient within their larger socioeconomic environment such as detailed in the figure below 2:3 by Dahlgren and Whitehead (1991).

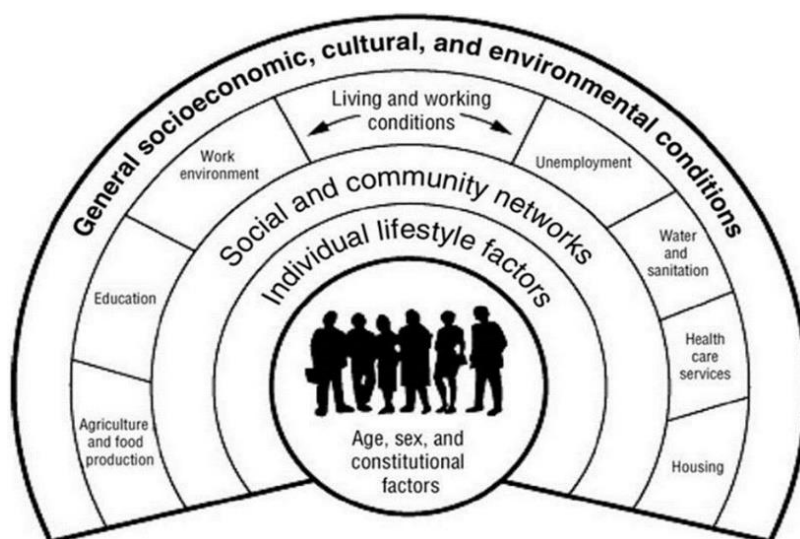


Figure 2:3 Socioeconomic model (Dahlgren and Whitehead, 1991)

This model depicts how the individual is situated within their social, economic, cultural and physical environment and how that determines their unique health context. The integrated nature of these contextual factors highlights the implications of inequalities in any of the areas which could have a chain reaction effect other areas, affecting the health outcomes of the individual (Coles, Wells, Maxwell, Harris, Anderson, Gray, Milner & Macgillivray, 2017). However, it is important to consider that these contextual factors are changing in nature and unique to each setting, which demands a dynamic approach to the implementation of health care interventions, with frequent re-evaluation and adaptation (Coles *et al.*, 2017).

2.4. Summary

Musculoskeletal disorders are the second largest contributor to physical disabilities in the global context, of which OA of the knee is the most prevalent condition. Physical disability due to OA of the knee impedes the functionality of the patient and has an impact on their occupational abilities, their social and community lives as well as their day to day activities within their home environment. These difficulties are amplified in rural settings where the patients are influenced by infrastructural difficulties and a lack of resources are considered the norm (Rhoda, 2016). Implementing a contextual, user friendly self-management programme could assist in the management of MSK related disabilities such as OA of the knee, improving their functionality and overall quality of life. This study will investigate the contextual factors that could influence the implementation of a self-management and education programme in the rural settings of the Western Cape. The following chapter will discuss the methodology used to conduct the study and answer the research questions.

Chapter 3

Methodology

3.1. Introduction

In this chapter, the research methodology and study design that were used to answer the research questions are discussed, along with the study procedure, data collection tools, data management and data analysis. The ethical considerations are also presented as well as the role of the researcher and the rigour in the qualitative study design.

3.2. Study design

An descriptive and exploratory qualitative research method with a phenomenological approach, as described by Creswell *et al.*, (2007), was used to conduct this study, as it was best suited to answer the research question. A triangulated data collection strategy was employed which included a demographic questionnaire that covered the geographical information, in-depth semi-structured individual interviews and focus group discussions as a mode of data collection (Mays & Pope, 2006). This approach was chosen to obtain the views of the participants with regards to the current rehabilitation structures available to them, to identify their needs and to explore the contextual factors that could influence the implementation of a self-management and education programme in their setting. The thoughts, feelings and opinions of the participants were sought, as having a better understanding of the individual (within their environment) as the ultimate end user of the self-management component of a clinical practice guideline (CPG) is important when considering implementation strategies (Brand & Cox, 2006; Vassilev, Rogers, Sanders, Kennedy, Blickem, Protheroe *et al.*, 2011; Kroon *et al.*, 2014; Ernstzen *et al.*, 2017). Environmental as well as personal barriers and facilitators were explored in depth as a result of the design of the study, which gave valuable insight into the contextual factors that could influence a community-based rehabilitation programme in these settings.

According to Creswell *et al.*, (2014) quantitative research is deductive in nature and allows for the evaluation of relationships between variables, identifying probable causes/ effects and is effective in comparing groups or generalising findings. On the other hand, qualitative research is defined by Miles *et al.* (2009:4) as “a source

of well-grounded, rich descriptions and explanations of processes in identifiable local contexts.” Qualitative research enables the investigator to obtain the thoughts, attitudes and feelings of the participants and explore the *why* and *how* behind their answers (Austin & Sutton, 2014). This method allows for description of past and possible future behaviour as it is linked to social phenomena within context and is the ideal method for data collection when exploring the possibility of implementing self-management rehabilitation programmes in a specific community (Flick, 2009). A qualitative approach was chosen for this study, as it allowed the investigator to obtain insight into the workings of the communities and to answer the research objectives related to the current needs of the communities as well as the contextual factors. A qualitative approach would not have allowed for the depth of insight into the contextual factors of the communities.

3.3. Study setting

The Western Cape Province in South Africa was chosen as the boundary area within which the study was performed. The study area was limited to this province due to the time constraints on this study as the primary investigator (PI) lives, works and studies within the province. Obtaining permission from the various local governing bodies to conduct the study at their primary health care (PHC) facilities as well as travelling to more than one province would not have been feasible during the time period that was chosen to conduct the study.

The Western Cape Province is known for its diverse mix of culture, all living in various geographical areas which are divided into urban, peri-urban and rural settlements. Even though there is a vast difference between the healthcare services available within the rural, peri-urban and urban settings in the Western Cape Province, this particular study focussed on the rural settings. People living in rural areas are the most disadvantaged with regards to service delivery, especially rehabilitation (Lehohla, 2011; Vergunst *et al.*, 2015). Rural settings are defined by the Local Government Budgets and Expenditure Review (2011) as sparsely populated areas in which people are dependent on the agricultural activities and natural resources. Rural areas across South Africa vary in their cultural and historical origin, where some rural areas were formed as designated homeland areas during apartheid and others that originated as a result of religious influence through missionary work (Neves & du Toit, 2013; Fay, 2015, Information on the Rural Areas Act, 2014). Differences in culture, geographical location and economic growth has shaped the communities over generations and have influenced the specific socio-economic factors for each specific community resulting in similarities and variances across South Africa (Neves & du Toit, 2013).

In the Western Cape, the rural areas originated as a result of the significant role of the church and the missionary stations which ensued in generations of families growing up in that area, creating communities around schools and churches that were close-knit and protective in nature. In contrast to peri-urban and urban areas, population densities in these areas tend to be low with minimal informal settlements as a result of the strong family ties and stability in these areas (Information on the Rural Areas Act, 2014). However, the individuals of these communities are still dependent on their nearest PHC facility for the majority of their health care needs, which includes rehabilitation (Rhoda, 2016). Due to the isolated locations of these rural areas, the rehabilitation professionals only visits the facility once a month, during which they need to attend to the various rehabilitative needs of the community (Bateman, 2012; Grut, Mji, Braathen & Ingstad, 2012). For the remainder of the time, the patients are dependent on their own knowledge on how to manage their symptoms and a self-management and education programme could be the ideal intervention for these individuals.

The Western Cape has an estimated total of 6.6 million inhabitants (11% of the total population of South Africa) and the three official languages spoken are Afrikaans, English and isiXhosa (Western Cape Language policy, 2017). The Department of Western Cape has identified 12 areas within the province as rural settings on their official website and the geographical locations chosen for data collection in this study was randomly selected from these 12 locations (Information on the Rural Areas Act, 2014). Random selection was done by the PI in the presence of two colleagues that were not affiliated with this study, by drawing the names from a container which contained all 12 of the identified rural areas. Four areas were selected randomly and fortuitously included a variety of the geographical areas of the Western Cape (West Coast, Eden and Overberg districts). These four areas allowed for one week of data collection per area and a total of one month was allocated for data collection. Within the time frame of this study, visiting four areas in four weeks were feasible. However, from the four areas selected, only three were visited by the PI as the fourth area has declined permission to conduct a study at their facility. By that time, data saturation was reached and a substitute area was not required. Appendix N has photos and a description of the area visited. Figure 3:1 presents the geographical location of the three areas that were visited.

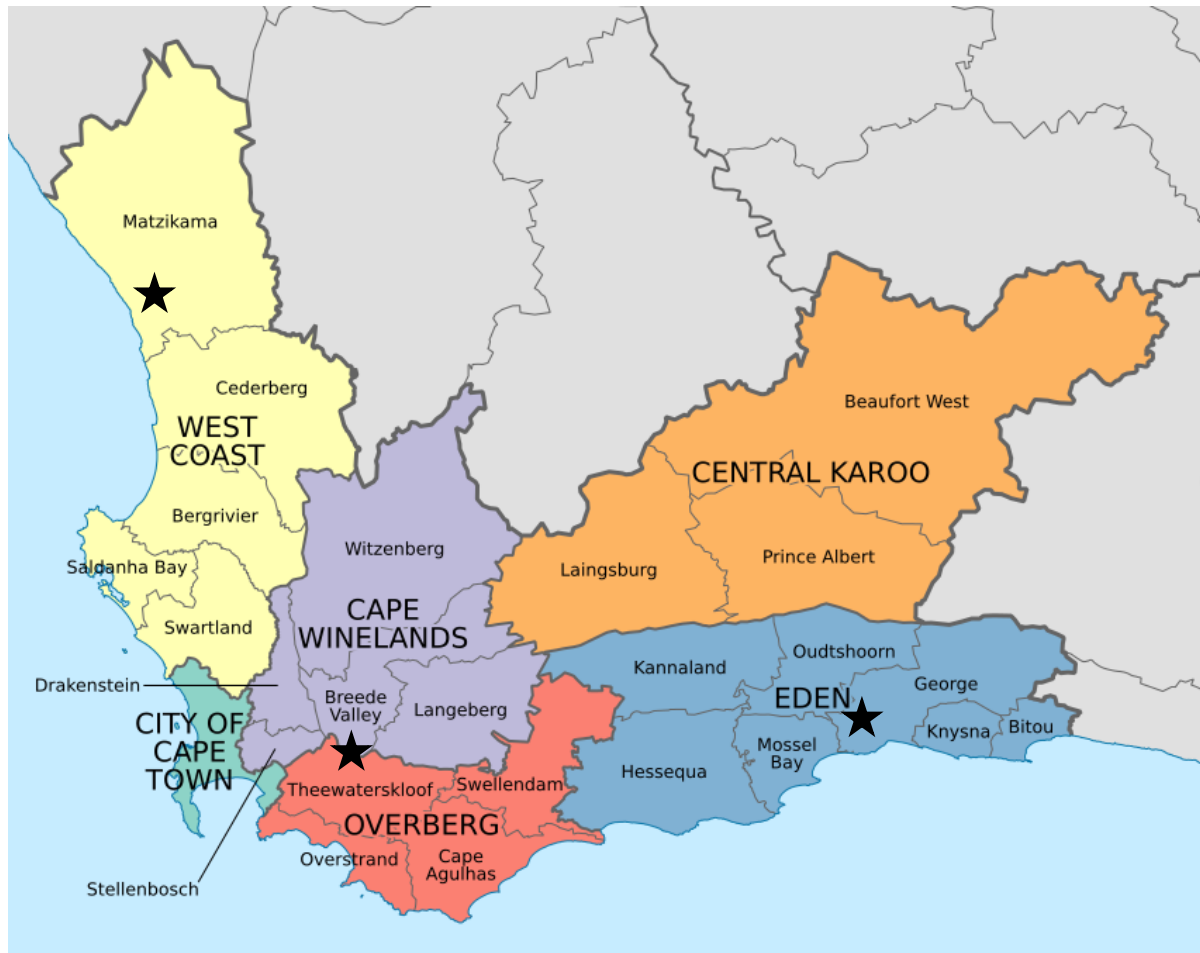


Figure 3:1 West-ern Cape, South Africa (Htonl, 2016)

The population data of the selected areas where obtained from Statistics South Africa (2012), which is a presentation of the data that was captured during the 2011 census. The latest available population data for the rural areas visited in the study and are presented in table 3:1 below, in combination with observations in the field:

Table 3:1 Population data (Statistics South Africa, 2012)

	Ebenhaezer	Friemersheim	Genadendal
District	Matzikama (West Coast district)	Mosselbay (Eden district)	Theewaterskloof (Cape Overberg district)
Population	1305	1235	5663
Population density (per km²)	1927	530	1427
Languages	Afrikaans (97.5 %) English (2.0 %)	Afrikaans (97.7 %) English (not provided)	Afrikaans (94.9 %) English (3.1 %)
Formal dwellings	98.5 %	90.9 %	88.8 %
Electricity for home use	99.8 %	92.5 %	96 %
Piped water inside	88.6 %	82,4 %	74.3 %
Clinic operational days	Tuesdays and Thursdays	Tuesdays and Thursdays	Everyday
Regular clinic staff	Registered nurse (n=2) Nursing assistant (n=2) Doctor (n=1)	Registered nurse (n=1) Nursing assistant (n=1) Doctor (n=1)	Registered nurse (n=2) Nursing assistant (n=3) Counsellor (n=1) Doctor (n=1)
Visiting allied health (monthly)	Physiotherapy Occupational Therapy Dietician Dentist Dental hygienist Clinical Psychologist Psychiatrist	Dentist	Physiotherapy Occupational Therapy Speech Therapy Audiology Dietician Psychologist Dentist
Nearest hospital	Vredendal (31 km) Tygerberg (337 km)	Mossel Bay (40 km)	Caledon (32 km) Worcester (96 km)
Transport available	Minibus taxi's	Minibus taxi's	Minibus taxi's

3.4. Study population

3.4.1. Inclusion criteria:

3.4.2.1. *Participants with knee OA*

- i. Participants must have been 45 years of age or older as the mean starting age of OA is estimated at 45 years of age (Prieto-Alhambra, Judge, Javaid, Cooper, Diez-Perez & Arden, 2014).
- ii. Male and female participants were included.
- iii. Unilateral and bilateral knee OA was included
- iv. Patients diagnosed by a healthcare practitioner with either symptomatic or asymptomatic OA of the knee (confirmed in their file at the clinic)

3.4.2.2. *Community health care workers*

- i. Working in the specified community.
- ii. Working in the community for longer than one calendar month as a newly appointed worker might not know the community and patients yet.

3.4.2. Exclusion criteria:

3.4.2.1. *Participants with knee OA*

- i. Patients with other disabling conditions (CVA, neural or muscular disease etc.) were excluded as their needs and clinical picture will be different.
- ii. Patients with OA of any other joints not including the knee.
- iii. Patients with Rheumatoid arthritis (RA) were excluded.
- iv. Patients with an unclear diagnosis in their files.

3.4.2.2. *Community health care workers*

- i. Not working in the specified community.

- ii. Working in the community for less than one calendar month.

3.4.3. Sample size

The aim of this study required in-depth data collection on the contextual factors of the environment as well as the personal factors of the people and the community at large. Individual interviews were chosen for the people with knee OA and focus group discussions were held with the community health care workers who could provide collateral information. The idea of collecting collateral information is to have accompanying/ additional information that could assist in the confirmation/ contradiction of ideas that emerge.

3.4.3.1. *Participants with knee OA*

Determining sample size in qualitative research is based on the study approach and data saturation (when no new categories and ideas are introduced during the interview of the participants) (Fusch & Ness, 2015). According to a review done by Guetterman (2015), the range of sample sizes included in health related phenomenological studies are 8 – 52, with a mean of 25 participants. In addition, he stated that some studies reported data saturation after 12 or 15 interviews, where other studies only reached saturation at 30-40 interviews. Creswell *et al.* (2007) however stated that anything from 5-25 participants should be sufficient. Considering the timeframe of this master's study and the recommendations of the sample size from the literature, 24 individual participants and four focus groups (one community health care worker group per area) were chosen as the sample size. However, after the first three areas were visited and 18 individual interviews were performed (with their corresponding three focus groups), data saturation was reached as no new information or concepts were presented during the interviews.

3.4.3.2. *Community health care workers*

Focus group interviews were performed in each geographical area and included all the CHCW that were available to participate. The proposed sample size for focus group discussions is between 6 and 12 participants (Rabiee, 2004; Fusch & Ness, 2015), but could include as little as 4 participants (Carlsen & Glenton, 2011). Due to the small size of these rural areas, it was not expected that the total number of health care workers would exceed 12 and it was decided that all of the workers that are available for interviewing would be included, with the maximum total of 12 CHCW per focus group.

3.5. Recruitment of participants

Once approval was been obtained from the Department of Health (DoH), the list of facilities (randomly sampled as discussed in section 3.3) which agreed to participate in the study was identified and contacted. During the risk analysis, the PI identified that obtaining a comprehensive database of patients with knee OA living in the selected areas might prove difficult, and a contingency plan was devised. The contingency plan ranged from the least biased and randomized method of participant recruitment to more biased options of recruitment. The PI was unsure of what she might find when arriving in these areas, therefore all possible methods for participant recruitment was planned for.

The table below (table 3:2) indicate the contingency plan in the order it was applied, however, the most effective method for recruitment of participants in these rural settings turned out to be snowball sampling. This non-probability sampling method employed the use of waiting rooms and word of mouth recruitment. The PI did not interfere with the selection of the eligible participants, however, the PI did enquire about community members that might be at work and could be a possible candidate in an effort to include more members of the community (such as the males and the younger demographic of patients). Searching for candidates were stopped after the required number of participants were reached per area, therefore the ratio of male vs female participants as well as the distribution in age could have been affected by any of these factors.

Table 3:2 Contingency plan for recruitment of participants

Contact with	How to obtain contact information	Participant recruitment method
Facility (PT/OT)	OA exercise groups (availability, dates and times)	No exercise groups available
Secondary/ tertiary hospital in the area	Recorded database of patients attending the hospital with knee OA	Some databases do exist where one could look up the ICD 10 codes, however, the patients attending the secondary and tertiary hospitals are usually end stage OA patients, and it was not desired to only have those patients in the study. This step was therefore omitted.
Facility PT/ OT	Recorded database of patients attending the facility with knee OA	PT/OT not available/ did not return phone calls and emails.
Facility nurse/ doctor	Recorded database of patients attending the facility with knee OA	No recorded database existed at any of the facilities
Community based health care workers	Recorded database of patients with knee OA	No recorded database existed at any of the facilities
Patients in the waiting room at PHC facility	Word of mouth/ advertisement	This was the method of choice as the participants were available immediately, and could give consent to view their files on the spot. They were also able to identify other possible candidates.
Old age home/ old age group	Word of mouth/ advertisement	This was not ideal, as most of the people at these groups was of advanced age, which reduced the chances of having anyone younger in the study. However, this option was used at the first site to find the final two participants when no other participants could be found.
Clinicians (PT/ OT)	Database by memory of patients that attend therapy for knee OA	This method was not needed
Nurses	Database by memory of patients that attend the clinic for knee OA	This method was not needed
Community based health care workers	Database by memory of patients that have knee OA	This method was not needed
Community based health care workers	Word of mouth search for patients	This method was not needed

3.6. Study procedure

The study made use of six steps which are demonstrated in the flow diagram (figure 3:5) below:

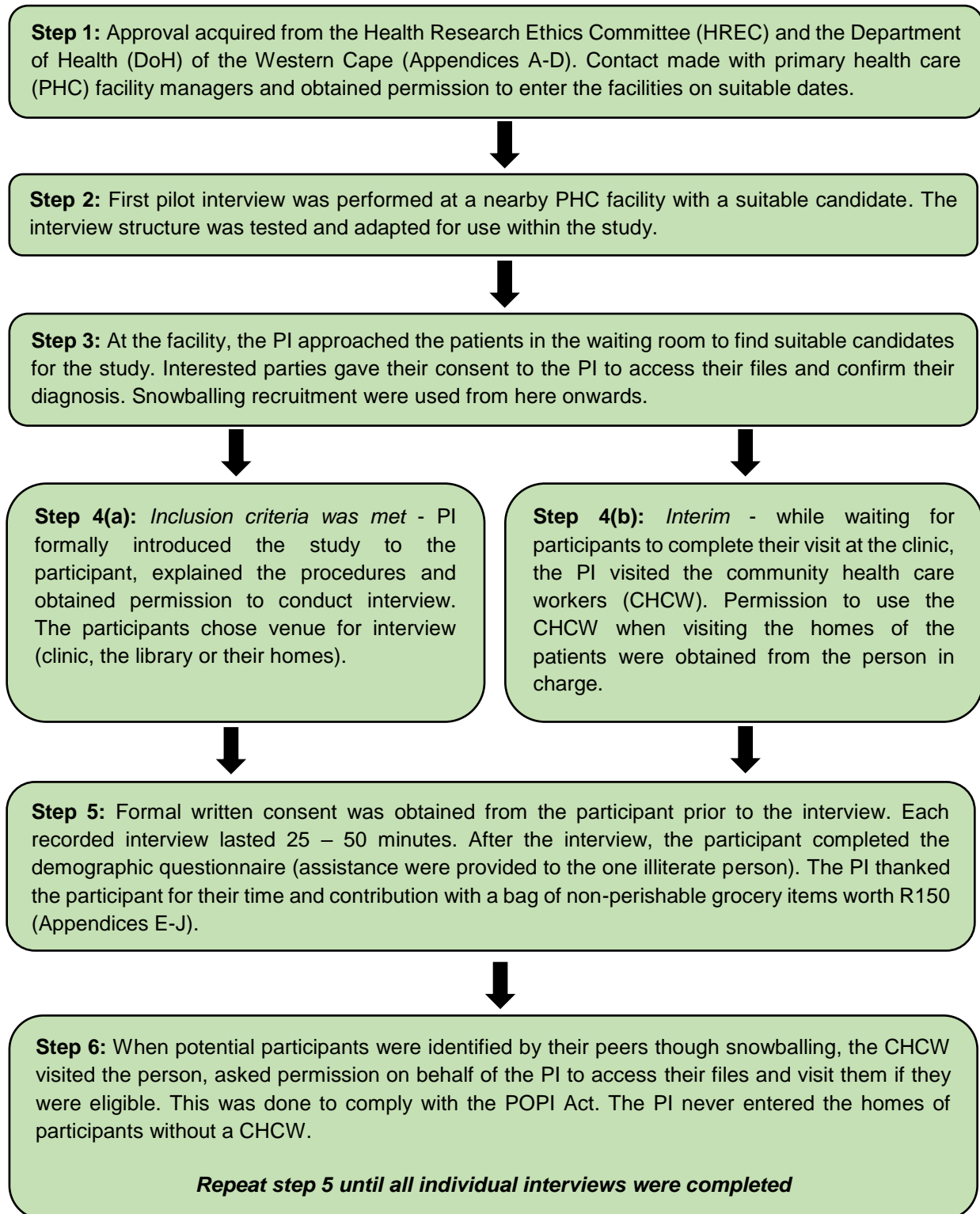


Figure 3:2 Study procedure

Step 7: Focus group interviews were conducted at a suitable time and venue for the CHCWs. Permission to speak to the group was obtained from their group leader. The interviews lasted 40-60 minutes. The PI thanked the participant for their time and contribution with a bag of non-perishable grocery items worth R150 (Appendices E-J).

Figure 3:3 Study procedure (continued)

3.7. Community participation/ consultation

Upon receipt of approval from the Western Cape Department of Health, the PI was supplied with the contact details of the district manager of each area. Each of the district managers were contacted for specific contact details of the facility managers of the specific PHC sites. A good rapport was built with the staff beforehand by consulting them on appropriate arrival dates and suitable times for entering the facilities. Upon arrival, the PI approached the staff (and the manager) at the PHC facility to introduce herself and inquire about their routine for the day as well as the appropriate person to work with for procuring the patient files and information. The PI also approached the community care health workers (CHCW) and asked for their assistance when visiting the homes of the participants. The PI and the CHCW worked closely for the next few days and the PI never entered the homes of participants without the presence of a CHCW, who introduced the PI and asked permission to enter. The PI also held a focus group discussion with the CHCW to obtain their perceptions and opinions, as they play an important role in the health and wellbeing of the community and could possibly assist in the implementation of an exercise and self-management programme. However, it should be noted that the CHCW would know who the individual interviewees were, and this may have influenced their responses in the focus group discussions.

3.8. Data collection tools

The aim of this study required in-depth data collection on the contextual factors of the environment as well as the personal factors of the people and the community at large. Individual interviews were chosen as a method for collecting data from the patients that are currently diagnosed with OA, to gain insight from their personal experiences and needs. Focus group interviews with the community health care workers (CHCW) were also performed to obtain collateral information as they work closely with the community and are the link between

the community and the clinic in many ways. Obtaining additional information from the CHCW on things such as the social structure and the community participation could enrich the data.

3.8.1. Demographic questionnaire

The quantitative data was collected using a survey type questionnaire to obtain the demographical information of the participant and contained close ended questions. In the pilot interview, this was completed before the interview, however, the PI realised that this provoked elaboration from the participant that should be on the recording. Therefore, the survey questionnaire was completed after the interview to prevent loss of valuable information from the recorded data. The demographic questionnaire were completed all the participants (individual and focus group), each with their own set of questions (Appendix I and J). The questionnaires were assessed for face validity by the researcher and a qualitative interview expert before and after the pilot interview.

3.8.2. Semi-structured individual interviews

The qualitative data collection was done using a semi-structured individual interview (Appendix G). The content of the interview guide were informed by the contextual factors of the ICF and were assessed for face validity by the researcher and a qualitative interview expert before and after the pilot interview. The interviews were conducted by the PI for the people speaking Afrikaans or English and each interview was 25- 50 minutes in duration. The interviews were conducted at a venue that the participants were most comfortable with (their home, the clinic, the library etc). All interviews with isiXhosa speaking participants would have been conducted by a research assistant that is fluent in isiXhosa. The interviews were recorded for transcription and data analysis.

Individual interviews with the participants with knee OA were chosen (as opposed to focus groups) to allow the participant to be honest in their account of the services offered at the clinic as well as their specific needs. The semi-structured interview is most frequently used in qualitative research which includes the use of an interview guide, using open ended questions, but allowing the researcher to explore themes as they emerge during the interview (Britten, Pope & Mays, 2006; Doody & Noonan, 2013). Focus groups create a complex social environment where personal characteristics (such as age, gender, and personal characteristics) might influence the disclosure of information and the interactions of the group affects the participation of the

individuals (Steward & Shamdasani, 2015). The individual interviews allowed the principal investigator (PI) to conduct open discussions with the participants and build a good rapport with the individual, which contributed to the quality of information shared and investigated. The interview questions aimed at obtain information about the current needs and service delivery in the area as well as the barriers and facilitators for the implementation of a self-management programme for knee OA, as seen by the community members themselves. The interviews allowed the participants to give their personal view on the subject and probing by the interviewer was done accordingly.

A pilot interview was conducted (Turner, 2010) on a patient diagnosed with knee OA from a local PHC facility and allowed the PI to identify additional questions to be added and redundant questions to be removed. This also allowed the PI to work on her interviewing skills as she was too leading in her questioning. After the initial two interviews were performed at the first area of data collection, the PI reflected on her questioning even more, and realised that questions had to be rephrased and to ask the participants why they say certain things or why not. This was applied to the successive interviews and improved as the skill of the PI developed over time. Member checking was done during the interview by repeating some of the answers given by the participant, in their words, and asking if this is what they meant. This way they can confirm if the information perceived by the PI is a true reflection of their words and meanings (Shenton, 2004; Britten *et al.*, 2006).

The aim of the interview was to determine what treatment the participants are currently receiving for their knee OA, to explore their individual needs with regards to their OA related health and to determine if their thoughts on the implementation of a self-management programme from a personal view.

3.8.3. Semi-structured focus group interview

After data collection from the participants with knee OA was completed, a focus group discussion was held with the CHCW to obtain their views on the contextual factors discussed during the individual interviews. The same procedure was applied for the focus group discussion which followed a semi structured interview schedule (Appendix H). The interview guide was adapted from the individual interview guide to include specific questions regarding the community and the CHCW role. The interview guide was assessed for face value by the researcher and a qualitative research expert. The possible barriers and solutions were also discussed, along with the possible role of the CHCW in the implementation of the current education and self-management programs as described in the CPG's for knee OA. The information gained from the individual interviews were

used to guide the focus group discussion, however, care was taken not to disclose any particular information that might lead to the identification of individual participants from previous interviews as the CHCW knew who was interviewed individually. Focus group interviews were chosen as the shared experiences of the group along with their combined opinion was sought and a wide range of ideas and perceptions could be discussed, providing bountiful and rich data (Rabiee, 2004; Palmer, Larkin, de Visser & Fadden, 2010). Unfortunately, within the context of a focus group, the conversation is shaped by the social interactions and dynamics of the group as a whole, which might have affected personal opinions from surfacing (Palmer *et al.*, 2010).

The aim of the focus group interview was to obtain a view of the community at large and to determine what social and environmental factors could influence the implementation of a self-management programme for knee OA.

3.8.4. Field notes, photos and diary

Even though this was not a formal data collection tool, the PI made field notes on all the processes and procedures followed during the data collection. The PI also took photos of the environment and kept a diary every day to describe all of her thoughts and feelings and to assist with the planning for the next day. These notes were consulted during the data analysis process to allow for deeper insight into the context of certain recorded data.

3.9. The role of the researcher

During the qualitative research process, the researcher plays an integral part as a data collection tool. The researchers background, qualifications, experience, personality, motives and perceptions influences the relationship built with the participants (Shenton, 2004; Britten *et al.*, 2006; Karnieli-miller, Strier & Pessah, 2009). Some of the participants enquired where the PI was from and if this research formed part of her degree/ studies. This might have influenced their perceptions of the PI in either a negative or positive manner.

In qualitative research, the aim is to move towards a patient-centred research approach, where the participant and the researcher play equally important roles in the data collection process. The researcher conceptualised the aims and objectives of the study and will do all the work to transcribe, analyse and write up the data, whereas the participant is the person whom without the study would not exist, as they provide the valuable

information. It is therefore important that the researcher creates a friendly and safe environment, without authority, in which the participant would want to share their stories and feelings (Britten *et al.*, 2006; Karnieli-miller *et al.*, 2009). In this study, the PI attempted to create a nonthreatening environment during the interviews to encourage the participants to express themselves. Upon introduction the PI stated that she is a physiotherapist. This was done on purpose to ensure the participants that she is part of the rehabilitation team and has an understanding for their condition. However, this might have also changed the initial power relationship in the interview if the physiotherapist was seen as part of the “authority” that is the medical practitioners (Karnieli-miller *et al.*, 2009). The PI aimed to assure the participants of her intentions to assist in the provision of improved care.

3.10. Data collection content

The semi-structured interview schedule was developed by consulting the latest clinical practice guidelines as well as the Ottawa reviews on the self-management of knee OA (Nelson, Allen, Golightly, Goode & Jordan, 2014; Meneses, Goode, Nelson, Lin, Jordan, Allen, Bennell *et al.*, 2016; Brosseau, Taki, Desjardins, Thevenot, Fransen, Wells *et al.*, 2017; Lane, Shidara & Wise, 2017). In 2016, Kruger-Jakins *et al.* reported on the development of a self-management programme for patients awaiting a knee arthroplasty. They combined the best evidence and created a patient workbook used in their Physiotherapy led self-management programme (Saw *et al.*, 2016). This workbook, along with all the other material on self-management programmes for knee OA were outlined and explored, and the key components were added to the interview schedule. The interview schedule were informed by the international classification of function (ICF) as a framework to explore the third and fourth objective of the study (WHO, 2003; Grotkamp *et al.*, 2012). Dziedzic *et al.* (2014) reported on an implementation study done using the National Institute for Health and Excellence (NICE) guidelines, and found that education, weight loss and exercise should be the cornerstone of each visit to the clinic for people with OA. This guide was used to explore the first and second objective of the study. The Osteoarthritis Quality Indicator Questionnaire (OQIQ), developed by Osterås, Garratt, Grotle, Natvig, Kjekken, Kvien *et al.*, (2013), were also consulted and to ensure that all the topics on the questionnaire are covered in the interview. The OQIQ was developed to measure the quality of care provided to people with knee OA.

3.11. Data management and analysis

The data collected via the digital voice recorder, was downloaded onto a password protected computer and a backup was placed onto a hard drive and stored in a locked cabinet at the Physiotherapy Division at the University of Stellenbosch. The consent forms were separated from the field notes and demographic questionnaires, and locked up for safe keeping in separate locations. All data processing was performed anonymously from this point onwards. After data collection was completed, all of the interviews were transcribed, validated and translated. Due to time constraints, the transcription and translation of the individual interviews were done by a professional transcriber. The focus group interviews were transcribed and translated by the PI to allow for development of this skill and immersion in the data as suggested by Sutton *et al.* (2015). All of the interviews were validated by the PI before coding was started. The validation included listening to the audio while reading the transcript in Afrikaans, and then reading the transcript in English to ensure that the translations were correct, after which the data was coded. The data was coded using ATLAS.ti (version 8) coding software.

A deductive coding approach with a framework analysis (Hsieh & Shannon, 2005; Pope, Ziebland & Mays, 2006) was used for the analysis process. The framework analysis involves the creation of a structure for analysis, based on the objectives of the study and the interview schedule, by which coding and sorting of information will take place (Rabiee, 2004; Pope *et al.*, 2006). Even though this is an organised approach, it is still flexible to be guided by the data (Pope *et al.*, 2006). By using the ICF framework to inform the interview schedule, the use of a deductive analysis was chosen to ensure that all the possible contextual factors (environmental and personal) were analysed according to the topics covered during the interview. The PI then created a codebook (Appendix K) based on the interview structure and the objectives of the study, and added extra codes as more themes emerged during the coding process. The first three interviews were coded separately by the PI and an experienced qualitative researcher, after which the coding results were compared for validation of the coding process. After the validation process, the PI continued to code the remaining transcripts independently. Field notes and the diary of the PI were also consulted during the coding and analysis process to allow the PI to reflect on the data that was not recorded on the voice recorder. This included the sights, sounds and facial expressions, which gave deeper insight and context to the data. After the coding was completed, the PI used the framework approach to search the data for co-occurrences and prominently coded content. The prominent data was extracted into Microsoft Excel (version 2013) spreadsheets according

to the objectives of the study and analysed for deeper insight. All the demographic information was inserted into a Microsoft Excel (version 2013) spreadsheet for analysis by the PI in consultation with a biostatistician.

3.12. Ethical considerations

Ethical approval for the conduction of this study was obtained from the Health Research Ethics Committee at the Stellenbosch University. Permission to conduct the study within the communities and at PHC facilities in the Western Cape was requested from the Western Cape Department of Health through the National Health Research Database (NHRD).

3.12.1. Consent

Each eligible participant were individually informed of the purpose and procedures of the study, and this information was delivered in the language preferred by the participant (Afrikaans or English). An informed consent form was read and signed by each participant on agreement of participation. Informed and written consent was obtained for collection of data, storage of data, data analysis as well as a report on the findings. The aim of the study was explained to the participant as clearly as possible as well as how the information would be processed and documented. The participants were encouraged to ask questions and engage in an honest conversation throughout the interview. Participants were notified that they were allowed to withdraw from the study at any time, without any consequences.

3.12.2. Confidentiality

The data recorded had no personal identification attached to it. Instead, a study reference number was allocated to each participant. The study reference number and respective participant name correlation was stored in a completely separate encrypted file. During the interviews and round table discussions, participants were addressed as “participant 1”, “participant 2” and so forth. No names were mentioned. Confidentiality was maintained at all times throughout the study and all decisions made was in the best interest of the participant.

3.12.3. Risk/ benefit ratio

There were minimal identified risks involved in participating in this study. It is possible that the interview could evoke an emotional response from the participant. The benefits of the information obtained in this study could allow for deeper insight and consideration of the contextual factors that could influence the implementation of a self-management and education programme, allowing for adaptation of these programmes.

3.12.4. Reimbursement

All the participants (individual interviews as well as the focus group participants) received a non-perishable food package as reimbursement for their time. The content of the package was detailed by a registered dietician to ensure that it contains food items that are nutritious, healthy and culture specific.

3.13. Rigour in qualitative design

Qualitative data collection is a constant process of reflection and further exploration by the investigator, allowing for flexibility within the process. Therefore, to ensure rigour in the process, certain considerations has be in place from the start of the project. Due to the nature of the data that is collected during qualitative research as well as the data collection procedures, critics have been sceptical of the reliability and validity of the data (Shenton, 2004; Mays & Pope, 2006). Compared to quantitative research which uses statistics and precise numerical procedures to ensure validity and reliability, qualitative research does not rely on expected outcomes. Qualitative research attempts to discover the unexpected truth and requires continuous insight and adaptation on the part of the researcher during the process (Mays & Pope, 2006; Creswell *et al.*, 2014). However, to ensure that the data captured is viewed as trustworthy and reliable, some strategies has to be implemented. Shenton (2004) and Mays *et al.* (2006) suggested four overarching criteria to ensure trustworthy results, and the PI aimed to incorporate as many strategies as possible to ensure rigour within the study.

3.13.1. Credibility

Also known as the internal validity of the study and the ability of the data collection methods to obtain the information that is intended (Shenton, 2004; Houghton & Keynes, 2013). The PI aimed to obtain credibility by incorporating the following:

- Using recognised research methods such as focus groups and semi-structured interviews.
- Building a relationship and an understanding of the community and PHC facilities by familiarising myself with the environment and operational procedures of the community beforehand. Contact was made before entering and upon arrival a day was taken to get to know the clinic, the staff and the CHCW. This added to the trust between the PI and the community and staff members, which lead to their cooperation and excitement about the project. This added to the quality of information obtained when speaking to the staff, the CHCW and the community.
- Sampling aimed to remove as much researcher bias as possible with the employment of random sampling where possible (random sampling of research settings). Even though the majority of the recruitment employed a snowballing technique, the researcher did not purposively select any participants. This improved the odds that the sample are representative of the entire community, even though the researcher had no control over the age or genders of the participants selected.
- Variation in data collection methods. This triangulation of data was obtained by using individual interviews, focus group discussions and observations within the field. The two interview strategies each has their own weaknesses and strengths, but the benefits of each were sought and the weaknesses were reduced by using both. The PI also made use opportunities to read documents related to the community and the individuals, as well as the notes within the files to gain insight into the attitude and behaviour of the individual, such as their commitment to their health and attendance of appointments. The diversity in perspectives gained from the participants with knee OA and the CHCW gave a more comprehensive and in depth view of the study environment and the reality of the situation in the communities.
- The PI aimed to get honest and upfront answers from the participants by encouraging them to speak freely and ensuring them that this information would not be shared with anyone in the community and that they are welcome to withdraw from the study at any moment. Care was taken to ensure that all potential participants were approached and treated equally and that they were encouraged to only take part if they truly wanted to.
- The PI used iterative questioning by rephrasing questions throughout the interview if certain answers appeared unlikely or untrue. This allowed the PI to ensure that all the questions were understood correctly/ within context and that all the answers given were truthful.

- Debriefing sessions with the supervisors allowed for the project to be scrutinized along every step of the way, and that all the possible concerns are addressed as soon as they appear. The PI also consulted various people within and outside of the department, each with different backgrounds and experience, who gave valuable insight into the project.
- Member checking as described by Shenton (2004) was done “*on the spot*” during the interviews where the PI repeated the answer given by the participant, asking them if this is what they meant and if I understood it correctly. This way the PI ensured that the participants’ true views are reflected on the transcripts and that some verification has occurred during the data collection process.
- The PI received qualitative interview skill training from a qualitative interview expert in order to improve the skills of the PI in conducting interviews.

3.13.2. Dependability and Confirmability

Also known as the reliability of the study, and its ability to produce the similar results if it was repeated in the same context with the same methods (Shenton, 2004) . However, in qualitative research, it proves problematic to repeat the procedure and produce the exact results, due to the changes that develops and unfolds based on the situation and the deep involvement of the researcher. Therefore it is argued that dependability and credibility is closely linked and that employment of sound credibility creates a well-grounded environment for dependability (Shenton, 2004). The use of corresponding methods such as focus groups as well as individual interviews assists in ensuring dependability. Furthermore, a report on the exact operation and experiences in the field could allow the reader to make a judgement on the degree to which sound research methods were used and how reliable the results of the study are (Shenton, 2004).

Due to the nature of qualitative research, the researcher plays an integral part in gathering the information and is seen as part of the data collection tools. Therefore, confirmability is concerned with the steps taken by the researcher to allow the views of the participants to be captured, rather than the imposed preferences of the researcher. It is inevitable that the bias of the researcher is intertwined with the project, and it is crucial that the researcher acknowledges their predispositions and how it influenced the decisions made regarding the methods chosen and the approaches taken (Houghton & Keynes, 2013). The researcher must make a clear distinction between the theories that derived from the data and the theories that did not come from the data, but rather the researcher themselves. An honest relationship between the researcher and the reader is key and an effort was made by the PI to remain open minded and receptive of the information at all times.

3.13.3. Transferability

This is also known as generalisability in quantitative research. The aim is to describe the context of the study as clearly and in depth as possible to allow for any interpretation to be made in context for application to similar situations (Houghton & Keynes, 2013). This is important since it is not possible to demonstrate that the findings of qualitative research can be applied to more general situations due to the small number of participants who are studied within their specific environments (Shenton, 2004). Therefore it is the responsibility of the PI to ensure that sufficient contextual information is provided and that no inferences are made towards the generalisability of the findings. The reader should be able to make a judgement on the similarity of their context and if the findings of the study is transferable to their situation.

3.14. Summary

In summary, this chapter dealt with the methodology chosen to conduct the research study. A Qualitative phenomenological approach was chosen to gain insight into the current rehabilitation offered at PHC in rural areas for people living with knee OA, as well as their needs. It was also used to determine the contextual factors that could influence the implementation of a self-management programme in the rural areas of the Western Cape. The data was collected using semi-structured interviews with the people with knee OA and focus groups discussion with the community health care workers of the areas. The areas for data collection were chosen randomly from a list supplied by the Department of Health, and participant recruitment were done by word of mouth at the clinic and through snowballing. The data was recorded on a digital voice recorder, after which the recordings were transcribed and translated to English. Data analysis followed a deductive approach according to a framework analysis to answer the objectives of the study, which will be presented in the next chapter, Chapter 4.

Chapter 4

Results

4.1. Introduction

This chapter will outline the results from the study which was obtained through a demographic questionnaire as well as semi structured interviews. The first section will be a presentation of the demographic information obtained from the questionnaire and the second section will be a presentation of the qualitative results from the semi structured interviews. The qualitative results are presented as per the study objectives. Quotations from the interviews are used to express the thoughts and feelings of the participants. The quotations from the individual interviews are labelled using the participant *number* and the *years diagnosed* with knee osteoarthritis (OA). The quotations from the focus group members are labelled using their participant number which is preceded by a FG (focus group).

4.2. Demographic profile of the participants

During the time of data collection at the three areas that were visited, a total of 37 potential participants were identified and approached. After permission was obtained from the potential participants to access their files at the clinic, 19 people were excluded as they did not meet the inclusion criteria. The first 18 people (six people per setting) that were eligible and available for interviews were interviewed. Exclusion of the other participants were done after screening of their files revealed that they did not meet the inclusion criteria: below the age of 45 years (n=3), had rheumatoid arthritis (n=5), had gout (n=3), had a stroke (n=1), had low back pain with referral to the knee (n=1) or no clear diagnosis in the file/ the file could not be found (n=6).

The first two interviews were used as pilot interviews and their data was not included in the analysis. In addition, only one male participated in the study despite some effort made to recruit more males. Even though the prevalence of OA is higher amongst females, the ratio is 2:1 for females, it could also be attributed to the phenomenon that males are not seeking health care as often as females (Gómez-Olivé, Thorogood, Clark, Kahn & Tollman, 2013). Three focus group discussions were held (one group per area) with a total number of 19 participants. Friemersheim, currently only have two CHCW employed, therefore the interview included only

the two of them. Even though this is not technically classified as a focus group, it was the entire population of health care workers in that area. The demographic information of the individual participants as well as the focus groups are presented in table 4:1 below:

Table 4:1 Demographic information of participants

Individual participants with knee OA		
Age, gender and home language		Individual (n=16)
Age of participants in years:	(median, range)	67.5 (49 - 84)
Gender of participants:	Female (%)	15 (93.75)
	Male (%)	1 (6.25)
Home language:	Afrikaans (%)	16 (100)
	English (%)	0 (0)
	IsiXhosa (%)	0 (0)
Level of education and ability to read		Individual (n=16)
Level of education (grade completed): median (range)		9 (0 -12)
Able to read (%)		15 (93.75)
Occupational variables		Individual (n=16)
Currently working:	Yes (%)	1 (6.25)
	No (%)	15 (93.75)
Current type of employment:	Nursing assistant (%)	1 (6.25)
Previous type of employment:	None (%)	2 (12.5)
	Care taker (%)	1 (6.25)
	Catering (%)	4 (25)
	Domestic (%)	4 (25)
	Factory (%)	4 (25)
	Farm work (%)	3 (18.75)
	Sewing (machine) (%)	1 (6.25)
OA related variables		Individual (n=16)
Years living with OA:	1-5 (%)	3 (18.75)
	6-10 (%)	2 (12.5)
	11-15 (%)	2 (12.5)
	16-20 (%)	0 (0)
	>20 (%)	9 (56.25)
Currently receiving rehabilitation:	Yes (%)	2 (12.5)
	No (%)	14 (87.5)
Have consulted (*) for their knee OA:	*Doctor (%)	14 (87.5)

	*Physio (%)	9 (56.25)
	*OT (%)	0 (0)
	*Nurse (%)	16 (100)
	*Dietician (%)	2 (12.5)
	*Specialist (%)	5 (31.25)
Technological and transport variables		Individual (n=16)
Owning a cellular phone:	Yes (%)	13 (81.25)
	No (%)	3 (18.75)
Is the cellular phone a smart phone:	Yes (%)	4 (25)
	No (%)	12 (75)
Competency on cellular phone:	median (range)	3 (1-10)
Owning a DVD player:	Yes (%)	9 (56.25)
	No (%)	7 (43.75)
Transport use:	Own transport	5 (31.25)
	Uses public transport	11 (68.75)
Focus group participants		
Age, gender and home language		Focus group (n=19)
Age of participants in years:	(median, range)	35 (27 – 52)
Gender of participants:	Female (%)	18 (94.75)
	Male (%)	1 (5.26)
Home language:	Afrikaans (%)	19 (100)
	English (%)	0 (0)
	IsiXhosa (%)	0 (0)
Occupational variables		Focus Group (n=19)
Years working as a CHCW:	< 1 year (%)	6 (31.58)
	2-5 years (%)	7 (36.84)
	5-10 years (%)	3 (15.79)
	10-15 years (%)	3 (15.79)

The results will be presented according to the objectives of the study. Figure 4:1 below is a visual representation of the major themes highlighted in the results:



Figure 4:1 Overview of results

4.3. Objective 1: Services received by individuals with knee OA

The first objective of the study was to determine the rehabilitation practices that are currently offered to patients living with knee OA in rural areas of the Western Cape. All of the patients attended the clinic upon which they had a consultation with the nurse as their first contact. The nurse usually refers the patients to the doctor for further management. Only two patients were not referred to the doctor. Upon consultation with the doctor, further referral was made to other members of the multi-disciplinary team (MDT). As can be seen in table 4:1 above, physiotherapy were underutilised, while more than 30% of the participants consulted a specialist for injections and surgery. From the view of the patients (and with collateral information from the community health care workers), the following were highlighted as the bulk of services offered to them by the current health care system (figure 4:1):

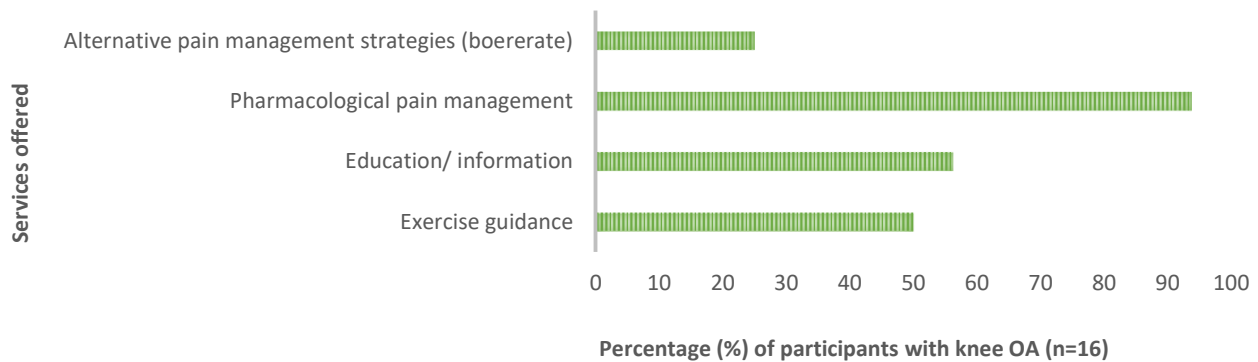


Figure 4:2 Services received from the PHC facilities

4.3.1. Exercise guidance

Of the eight participants who received some form of guidance on exercise, only five received exercise specifically for their knee OA. Two participants had a total knee replacement (TKR), and were treated by the in-hospital physiotherapist for one session before returning home. Both did not receive physiotherapy as a pre-operative intervention, and were discharged with a home programme containing advice and exercises. One other participant received a booklet with information from the physiotherapist at the clinic. This was the only participant who spoke of receiving any formal rehabilitation and follow up by a physiotherapist.

"She gave me physiotherapy, but it was tough. She was hard on me, saying you must do this, you must do that. I also received a booklet." (Participant 10; >20yrs)

4.3.2. Education

This section was approached with a broad question about the information they received at the clinic/ from any health care professional. Some of the participants were able to answer this question without guidance and gave insight into what they have been told. Nonetheless, most of the participants needed further probing into specific categories of information and appeared oblivious to what they should have received. Half of the participants received some form of education/ information, however, the other half stated that they did not receive any information at all. Unfortunately, only two (12.5%) of the participants stated that they were given specific information on the diagnosis, with explanations of what arthritis is. The information received can be categorised as demonstrated in figure 4:2 below:

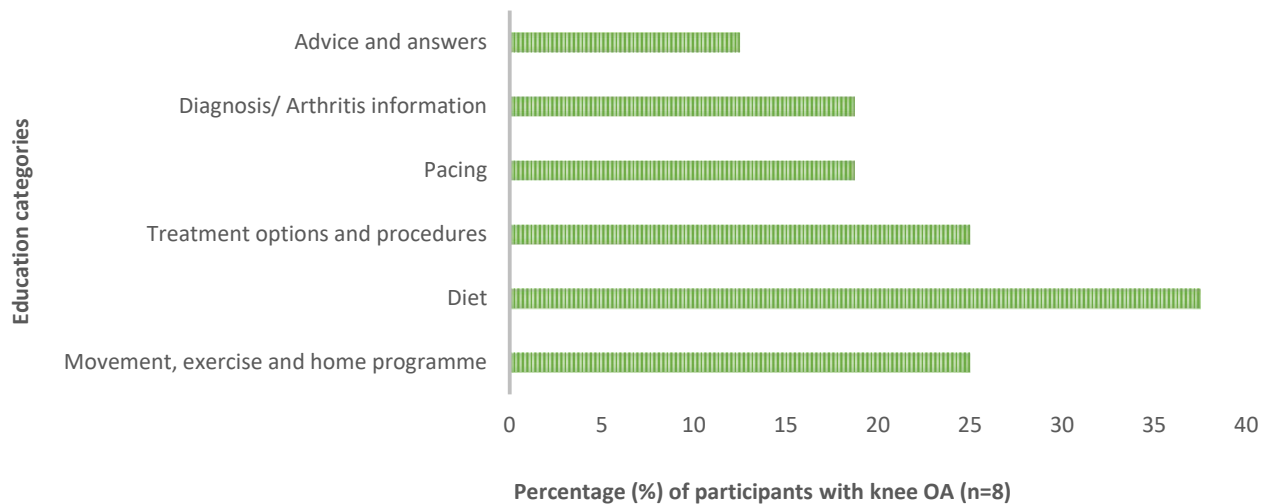


Figure 4:3 Information received at PHC facility

Most of the participants who received information, received some guidance towards a healthier diet. Remarkably, only two (12.5%) participants consulted a dietician and the remaining fourteen (87.5%) received their guidance from the doctor, the nurse and the physiotherapist, even though most of the areas had a visiting dietician. Interestingly, even though the participants received their education/ information from multiple health care personnel, the most prominent source of education/ information appears to be the doctor, as illustrated by the figure 4:3 below. This was followed by the Physiotherapist, the nurse, the specialist and the dietician:

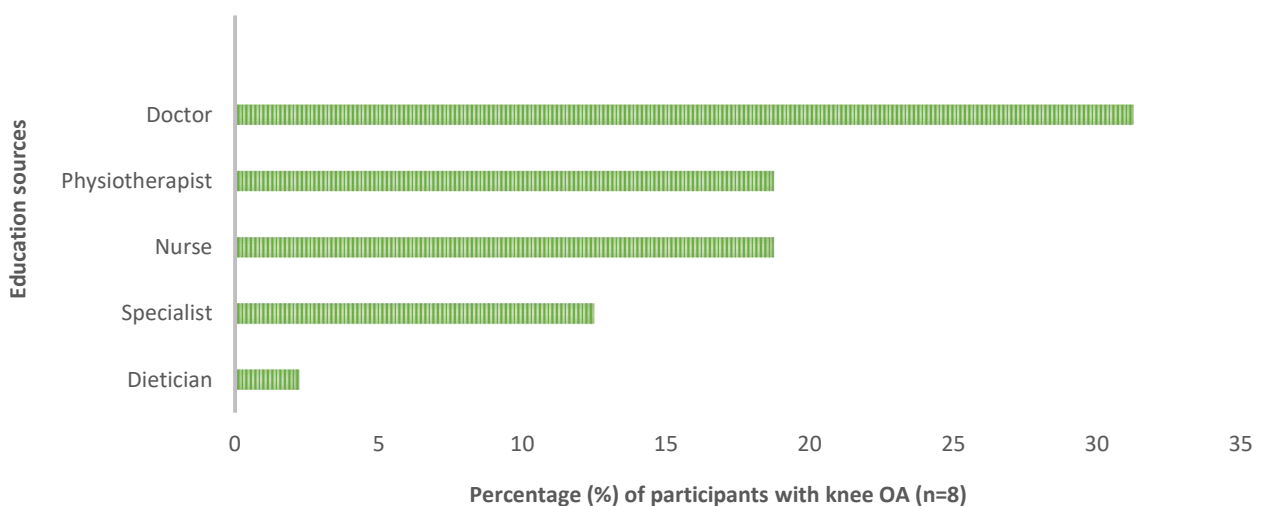


Figure 4:4 Sources of information

4.3.3. Pharmacological pain management

In this section, the participants were asked what they currently receive for treatment of the knee OA. The responses were mainly focussed on the pharmacological interventions, and will therefore be presented as such. The majority of the participants responded by listing the medication that the doctor prescribed them, while the remaining few stated that they are not receiving any treatment for the knee OA. The following figure 4:4 displays the pharmacological interventions that the participants are currently receiving as a form of pain management:

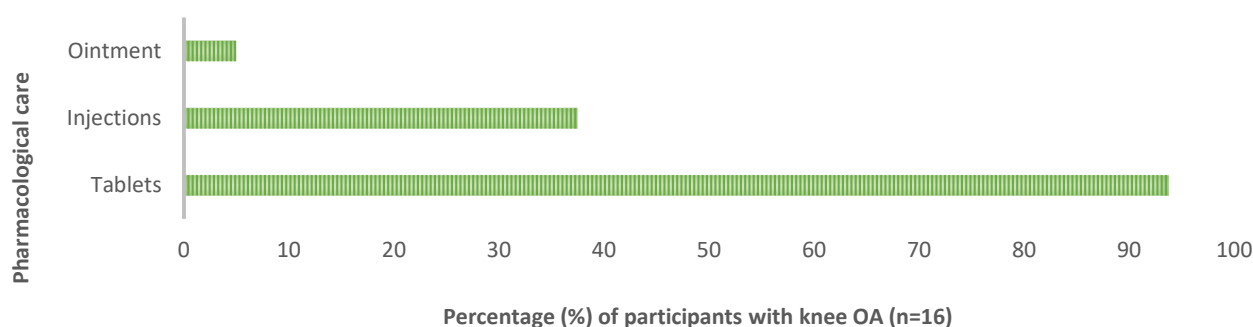


Figure 4:5 Pharmacological interventions

As can be seen in figure 4:4, tablets are the main pharmacological pain management intervention that is provided to the participants. The tablets they receive includes NSAID's, steroids, opioids and paracetamol. Some of the participants even buy their own pain medication from the pharmacy on top of what they receive from the health care personnel. A few of the participants appeared to be under the impression that the tablets they are receiving is a form of treatment, rather than the pain management intervention that it is.

"I'm now getting Adcodol from the hospital. I drink it and trust that it will help me."

(Participant 13; 5 yrs)

4.3.4. Summary

In summary, the participants with knee OA reported that the current treatment they receive from their primary health care facilities include exercise guidance, education, pharmacological pain management and some

assistive devices when needed. One participant received formal rehabilitation with follow up by a physiotherapist. Only half of the participants reportedly received some form of education such as dietary advice, the importance of movement, information about the disorder and treatment options. However, less than half received exercise guidance which did not include formal instruction from a physiotherapist. Almost all of the participants received medication as part of their pain management and no alternative symptom management strategies were offered by the medical personnel from the PHC facilities.

4.4. Objective 2: Needs of the communities

The second objective of the study was to identify the rehabilitation needs of the people with knee OA living in the rural areas of the Western Cape. From the discussion about the current treatment that is offered to the participants with knee OA, their needs with regards to rehabilitation and management of their knee OA was explored. The needs were classified according to the following themes: rehabilitation, personal wellbeing and systems and services. These themes are presented below:

4.4.1. Rehabilitation

The rehabilitation needs that were evident from the study included education, exercise, improved mobility and coping mechanisms.

4.4.1.1. *Education*

During the interview, the biggest uncertainty and need were demonstrated in relation to the participants' lack of education and understanding about their own condition. The overwhelming majority of participants verbalised their need to know more about their diagnosis and the management thereof. Three principal categories emerged:

Education on disease	Disease management	Diet
<ul style="list-style-type: none"> • What is arthritis? • Symptoms • Disease progression 	<ul style="list-style-type: none"> • Symptom and disease (pain) management • Do's and don't's • Pacing 	<ul style="list-style-type: none"> • Tell me exactly what to eat and what not

i. Education on disease

The majority of participants expressed their need to know more about the condition itself, and would like to understand where it comes from, why they have arthritis and what is going to happen to them. They stated that they were merely told that they had the condition and that nothing can be done for them. The knowledge of the health professionals appeared questionable, as they contributed to the myth that the disease are due to old age and that nothing can be done:

"They haven't told me where it comes from. They only say it's from the cold and we worked a lot in the fields." (Participant 8; 10yrs)

"Okay, the doctor tells me they can't do anything about it. It is just a lifelong pain that you have to bear." (Participant 12; >20yrs)

"And to tell me what the cause is. I want to know about things like that." (Participant 9; >20yrs)

"Oh so many times have I asked the Lord whether this is going to be my fate that I will become paralyzed." (Participant 7; >20yrs)

ii. Disease management

At least half of the participants demonstrated a lack of understanding on how to manage their condition and none of the participants knew how to manage their pain with alternative strategies (except the "boerate", which will be covered in section 4.6.1.2.v.). They were only aware of the pain medication that could assist with their symptoms management and were unsure which activities would contribute to the progression of the disease or how to pace themselves:

" Then I must take three of those tablets as well as three Panado's, only then I feel my legs... Yes. But okay, they told me the one was going to infect the other one later on. Is it true?" (Participant 12; >20yrs)

"If I walk the one day, the following day I am unable to walk again. Then I must stay at home." (Participant 6; 4yrs)

"Sometimes I feel, I don't know, I just lay down because if I walk, if I walk too much then it's very painful at night." (Participant 16; 13yrs)

"You see? Like stay away from this, or don't do this or that, do it like this." (Participant 9; >20yrs)

iii. Diet

It was evident that some participants did not know the specifics of a balanced and healthy diet, and expressed that they would like to know exactly what they should eat and how to avoid the "trigger" foods:

"Even if it's to lose weight I will also do it. But just give me a prescription of how I should have to lose weight, I'll do it too, but just prescribe on how I should eat, I will do it." (Participant 7; >20yrs)

"What I want is if you could tell me what type of food trigger arthritis then I will ..." (Participant 15; 1yr)

The need for education about OA were also expressed by the community health care workers as they themselves lack the understanding of the disease and the management thereof:

"I only get to see the doctor in two weeks. Now I must see the physio after doctor, now I wait for another month or two. In the meantime my knee is destroyed by the time I get to see the physio." (Participant FG17)

"The once a month receiving exercises is not going to help you. You cannot give your rusty knee exercises only once a month. The people are very uninformed about arthritis, because I, myself are uneducated about arthritis. I only know it is your joints that pain, that is all. And then I don't know where it comes from or how it get started and all that " (Participant FG19)

4.4.1.2. Exercise

It was evident that exercise was not seen as a form of "treatment" by the participants with knee OA and they appear unaware to the benefits of exercises for their condition. When asked about their exercise habits, some

of the participants responded that they did not do their exercises anymore or never even received exercises from any health care professional. After learning that exercise could help them manage their symptoms, ten participants stated that they feel they needed exercise and would like to receive a structured exercise programme. The focus groups confirmed that they were not aware of the people doing any exercises for their knee OA and thought that they should at least have a page with instructions for exercises to help them:

"No. No one has yet told me about what exercises are good at reducing the pain."

(Participant 15; 1yrs)

"I need the exercise because I'm already 53 and my body gets stiff from sitting around and doing nothing." (Participant 4; >20yrs)

"I'll do that also (exercise). Just as long as it will help my legs." (Participant 7; >20yrs)

"I don't know if they know what exercises." (Participant FG1)

"Because a physio could have given her a page so long, do these exercises and then I see you in a month and see how it goes." (Participant FG17)

4.4.1.3. Improved mobility

The majority of the individuals expressed their need for improved mobility as their mobility has been significantly affected by the OA in their knees. The reduced mobility has restricted their participation in activities which they were used to doing, and in some cases it also affected their confidence:

"I'll go to the shop here and buy two containers of milk and a bag of sugar then it takes about half an hour to walk home from there. No, I can't carry heavy stuff. I used to do a lot of things that I can't do anymore and don't want to do anymore. It's too heavy... I used to do much walking and I miss it now. I can't walk so far anymore." (Participant 14; >20yrs)

"Not always, but I'm so afraid of falling... And it's difficult for me to walk to church because it feels as if my knee wants to give way." (Participant 13; 5 yrs)

"Sometimes I say, I'm too scared to walk because [unclear] and then it just gives way." (Participant 11; 7yrs)

4.4.1.4. *Coping mechanisms*

Some of the participants mentioned their poor coping mechanisms when they have pain. One participant was awaiting total knee replacement (TKR) surgery for 10 years, and it can be argued that she could have used self-management strategies to help with symptom management while she waited:

"I sleep badly. I sleep very little because of sudden pain that I get and I must take tablets for that, Stilpane tablets, which is also not good to constantly take. So my real problem is that I sleep very little lately... When I have pain I light a cigarette. I'm still struggling to give that up. It is a problem." (Participant 9; >20yrs)

"Whether it's nine o'clock or eight o'clock in the morning, I go and I lie down. My time is my own." (Participant 13; 5yrs)

4.4.2. Personal wellbeing

The needs in this theme are related to the wellbeing of the participant and their need to receive personal attention for their condition. It was also expressed that they would like to feel good again and not live with the pain and discomfort they currently experience.

4.4.2.1. *Personal attention*

Five of the participants expressed their need to receive personal attention from the staff at the clinic when they attend their appointment for the symptoms in their knee:

"Yes. They could at least pay more attention to my knee." (Participant 6; 4yrs)

"Yes. I feel they should show more interest. I don't know how to say this, but they are giving me too little." (Participant 16; 13yrs)

"If I don't ask for the results they don't tell me." (Participant 13; 5yrs)

4.4.2.2. *Feeling good*

Half of the participants also stated that they have a need to feel good again or to do the things they used to enjoy doing without the constant concern for their pain. This appeared to create anxiety within them, greatly affecting their feeling of self-worth and their mental wellbeing:

"But I want to do something. I don't like to just sit and do nothing. So I'm 66 now. I will be 67 and one would like to have a few minutes of feeling good... You worry if you want to work in your garden or want to do anything else at home and you worry whether you will be able to this and that tomorrow again." (Participant 9; >20yrs)

"I don't feel myself anymore. Four years ago I could still do everything, but I feel with the arthritis a part of my life is missing because the things I could do, I can't do anymore... Ooo, I long for it. I did all my work myself. My garden and everything. It's a little neglected now because I need someone to do that for me." (Participant 13; 5yrs)

"I struggle to do it but I do it my way. Because visitors could come and then they'll see that my house is still not cleaned. I clean in my own way. I always kept it tidy." (Participant 4; >20yrs)

4.4.3. Systems and services

Some of the participants expressed their frustration with the system and the services they receive from their health care facility. These were mostly related to the lack of resources that they had to cope with on top of poor service delivery and long waiting lines at the clinic. They also felt that they should receive more in terms of their treatment, which was evident in their statements that they are "only" or "just" receiving these treatments:

"... or give something stronger for the pain or something like that... And then they don't even have tablets here, or nothing else. Then I must just walk back home... The doctor was supposed to come, but he didn't come and I still have not heard the result of the X-rays." (Participant 6; 4yrs)

"Had a lot of pain. I always went to the clinic or to the specialist then they just gave me injections... No, then I just get the tablets. Tablets and the ointment " **(Participant 3; >20yrs)**

"That's it. Only painkillers for my legs. They only gave me ordinary painkillers " **(Participant 7; >20yrs)**

"...then they merely told me it's arthritis and prescribed painkillers. Then I didn't go again." **(Participant 18; 12yrs)**

The focus groups also confirmed that there are long waiting times at the clinic and that the people are not receiving the treatment they should. However, they also felt that the community could be more understanding and patient as the services is free of charge:

"Uninformed. And impatient. This community is very impatient if you talk about coming to the clinic, does not matter with what type of pain. He will turn around at the door and then only will he come and sit at the clinic for those hours. Because the people are very impatient and ignorant, and not just with regards to arthritis, with everything health related... And since you are receiving the service free of charge, I think you cannot be judgemental about it. Because it is free...But now you are not willing to wait, you need the help, but you are impatient so now you live with the pain for the next few days. You are only putting yourself at a disadvantage." **(Participant FG17)**

"The personnel where too few. And the pressure from the community is too great at the end of the day. And if one sister has to attend to the needs of forty people, I believe that she will not be able to give the support they deserve to all forty people. The personnel are under pressure, the community is impatient, ill and impatient." **(Participant FG19)**

4.4.4. Summary

When exploring the needs within the community, the participants felt that they did not have sufficient knowledge about the condition which should have been provided by the health care professionals. This lack of knowledge was demonstrated by their poor insight into the effect of the disease and the progression. They were also oblivious to the any alternative treatment strategies (other than pain medication), and some

participants were unaware that the medication they are drinking are only for pain and not to cure the condition. It was particularly concerning that one participant thought she will become paralysed from osteoarthritis.

The lack of education and exercise were also evident in the poor coping mechanisms employed by the participants in this study. In addition, the participants felt that they are not receiving enough from their clinic. The concern for infrequent visits from rehabilitation professionals and the lack of appointment availability was highlighted along with the long waiting periods to see the doctor. Additionally, they travel far distances to the clinic, only to find that they are out of stock and will not be receiving any medication. This was discouraging to the participants, as they did not feel supported by the system. However, one of the focus groups stated that the people in the community are not understanding of the situation that there are too little staff for the amount of members in the community, they should therefore be more patient for the free service they are receiving.

Apart from their rehabilitation needs, the participants in this study also expressed needs related to their personal wellbeing. A constant concern about their pain and functional inability have also affected the participants' sense of self-worth. They expressed their wishes to be able to do their previous functional activities which included leisure as well as domestic chores.

4.5. Objective 3: Self-management implementation barriers

The barriers to implementation of a self-management and education programme in the contexts explored, were divided into environmental and personal factors, with the appropriate subdivisions. Since one of the concepts of a self-management programme is to have the information presented to a group of individuals, who could participate in exercises together and continue to meet for support at regular intervals, this idea was presented to the participants as a possible intervention. Table 4:3 below illustrates the factors that were highlighted as possible barriers:

Table 4.2 Self-management implementation barriers

Environmental factors		Personal factors	
<i>Services</i>	<ul style="list-style-type: none"> · Security · Transport · Continuity · Group leader 	<i>Attitudes</i>	<ul style="list-style-type: none"> · Attitude towards health · Compliance and ownership
<i>Attitudes</i>	<ul style="list-style-type: none"> · Community attitudes · Division 	<i>Social Isolation</i>	
<i>Finances</i>	<ul style="list-style-type: none"> · Fees · Transport · Mode of information delivery 		

4.5.1. Environmental factors

Environmental factors are classified (according to the ICF) as all the physical and social aspects related to the environment in which people live. The following factors were highlighted as possible barriers within the environment that the participants live in:

4.5.1.1. *Services*

These include the barriers related to the service within the environment of the participant and related to security, transport and continuity.

i. Security

Although most of the participants stated that it is still fairly safe in their communities, they did mention that the day time would be most suitable for a self-management group gathering, as it would be unsafe if it was held in the evening. Walking outside for exercise should also be done with some caution.

"There's also certain times in the day that you could do it. One must also not take a walk into the woods here by half passed six, seven o'clock because it's already getting dark then. Then it is unsafe." (Participant 7; >20yrs)

Yes. Genalers is not bad, as long as one walks during the day. Yes, it's safe. (Participant 15; 1yr)

ii. Transport

Transport in the communities were highlighted as a problem for those who are unable to walk far. This was the greatest concern that were emphasized by the focus groups, as most of the people do not have their own transport and relied on the public transport that is available. In these rural areas, the public transport consists mostly of minibus taxis, which was costly even for short distances travelled:

"To get the people here – transport is a problem. One doesn't even travel two kilometre then they charge you R50. From Berg Street to the clinic they charge R100." (Participant 15; 1yr)

"The only real problem would be, that if the person is unable to walk, they will struggle to get here..." (Participant FG17)

"If it has to be at one point, a central location, then the distance would be a problem. Because a lot of people talk, and then they will complain that there are no transport and they will not be able to get there." (Participant FG3)

iii. Continuity

Continuity of care was a concern voiced by the members of the focus groups who felt that the physiotherapist will not have time to pay attention to a programme such as this. In addition, they felt that a trained peer would not continue with the programme long term without compensation:

"It is someone new every time [physio]." (Participant FG1)

"Then the physio comes. And there are a whole bunch of people then that person cannot see all of those people once a month." (Participant FG19)

"And on the one hand one is creating employment for that person and the club will remain active because the person is receiving compensation... Because compensation may help to sustain this, and if the person doesn't receive compensation he may come once or twice

and then think, I'm not getting anything for this, why must I go? Nowadays people no longer work for free" (Participant 6; 4yrs)

iv. Group leader/ Community champion

Ideally, the physiotherapist would be leading the community self-management and education programme, however, due to the infrequent visits from the physiotherapists in these areas, alternative options for leadership were explored in the form of a trained community champion. A few participants expressed their negativity towards the CHCW as a possible option for delivering the programme due to past experiences with the CHCW and their change in scope of practice. Some of the participants appeared negative towards the physiotherapist with a perception that going to a physiotherapist is a painful experience:

"They only visit and then we must sign every time which just indicates that they were there (CHCW), but they don't really do anything." (Participant 5; >20yrs)

"Because compensation may help to sustain this, and if the person doesn't receive compensation he may come once or twice and then think, I'm not getting anything for this, why must I go. Nowadays people no longer work for free." (Participant 6; 4yrs)

"Sister, to be honest, no (not going to the physiotherapist), because that lady who was sitting next to me, when I told her, and she is also a large woman and struggles with her back and legs, she said no, she's not going to let herself get hurt." (Participant 7; >20yrs)

"They will complain that they are sore." (Participant FG5)

However, one focus group felt that this programme will only work if it is presented by a professional person such as a physiotherapist, as the members of the community will not attend if it is presented by members of the community or CHCW's:

"They will cooperate more if the programme is presented by you (the physiotherapist)... No, they are now used to us. Who are we to give them exercises." (Participant FG4)

" They have more trust in a trained person. " (Participant FG1)

4.5.1.2. *Attitudes*

The environmental attitudes consists of the attitudes of family, friends, neighbours and society surrounding the participants. This includes the community attitudes as well as social differences which could influence the participation in a self-management and education programme. The attitudes of the people were explored during the interviews and a majority of the participants commented on the other members within their community. A concern was raised about the possible lack of attendance in a group setting. One participant even eluded that the knee OA group must not do their exercises outside in the open, as the other members of the community might comment on their activities in a negative manner. In some areas there has been a previous attempt at an exercise group, however, it has failed due to poor attendance:

"Because people, I believe, don't believe in this type of thing." (Participant 5; >20yrs)

"Why should I go and exercise and why must I go and sit there to talk. That's how they are here... I don't know whether they will cooperate. As I say, they are very stubborn "
(Participant 16; 13yrs)

"Oh because if we're out there in the street this one will say did you see where this one is walking, look at what they are doing... We exercise and we know that we must come here and we have no problems in this group. We just do our thing. But the people don't turn up."
(Participant 4; >20yrs)

The focus groups confirmed that there are be people in the community with negative attitudes, and that some of them would rather stay at home, as they will question the benefit from going to a support group and learning about the condition. It was also felt that the participation will decrease if the intervention is held too often and should be limited to once or twice a month. Incentives such as refreshments during the group meetings should also be considered:

"And the man will go with that thought that at the end of the day it is not going to make me better, so even if it does improve a little, what will I gain in attending. Then I could just sit at home and do my exercises at home. Rather than having to walk that far to attend a support group where we all get together" (Participant FG7)

"Some of them that will be positive and negative. They do not have time for exercises."

(Participant FG4)

"Or for example twice, say twice a month. I cannot go every week on a Tuesday or Wednesday, something might come up and then I cannot make it. It will be good, not too often." **(Participant FG17)**

"Will there be refreshments? " **(Participant FG3)**

In addition, the PI noticed that there was a division among community members in one specific area. It appeared to be a sensitive topic, however, the participants disclosed that there are people in the community who would not talk to one another (mostly the elderly people) due to political or religious differences. In addition, job insecurity has created additional division within the community which may influence their willingness to participate in a self-management programme with opposing members of the community:

"Yes, it's like that here but it's amongst ourselves here... but we are different." **(Participant 4; >20yrs)**

"And then job creation projects where only certain people can get the job, and things like that. That also causes a separation in the community, because everyone is in need." **(Participant FG4)**

"And the elderly are not like the younger people that will talk to one another... And then it is more about churches here. This one is attending that church, and that one is in another church, so we don't mix with one another " **(Participant FG9)**

"There are bad blood between them for the rest of their lives, till the day they die [elderly people]. " **(Participant FG2)**

4.5.1.3. *Finances*

When asked about possible barriers to implementing a self-management programme in their area, some of the participants stated that there should not be any membership fees involved. The people were also

concerned about the cost of transport if they cannot walk to the designated central point, and in some areas, they also mentioned that certain venues around town is not available to the community for free.

"And if you invite these people to the talk or the presentation, you must not tell them to bring a ten rand, because that is bread money. Then they will not come." **(Participant FG17)**

"To get the people here – transport is a problem. One doesn't even travel two kilometre then they charge you R50. From Berg Street to the clinic they charge R100." **(Participant 15; 1yr)**

"There are plenty of places available, but there is a fee involved." **(Participant FG17)**

In addition, the mode of information delivery were discussed, and possible financial barriers have been identified. Previous studies have delivered their content in the form of a booklet or a DVD, and considering the current advancements in technology, information could also be presented on a smart cellular phone application (App). Although, 15 (93%) of the participants were literate and would be able to read information and instructions given to them, only three (18%) participants owned a smart phone, and 9 (56%) of participants had a DVD player (figure 4:5). As stated by one participant, not all of the individuals in the community had the privilege of owning a DVD player or a smart phone. This would therefore influence the mode of information delivery which could be used for these individuals.

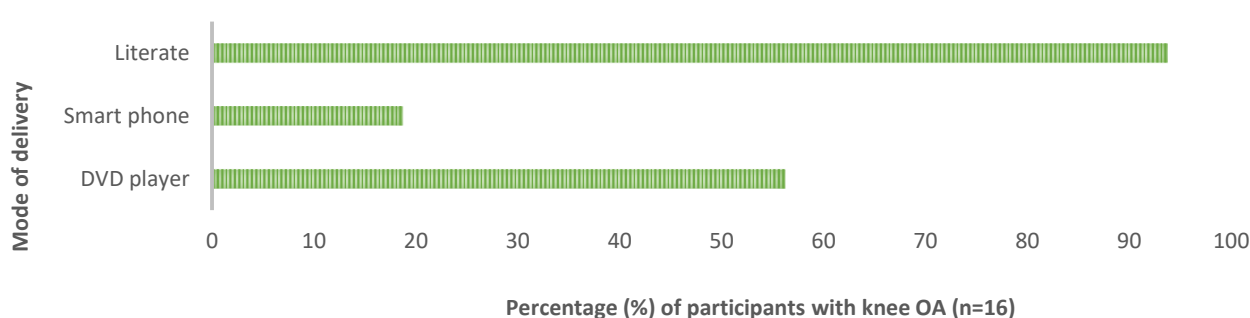


Figure 4:6 Mode of information delivery factors

4.5.2. Personal factors

These are the factors related to the individual themselves such as their attitudes towards others, their own health as well as their mental wellbeing and life situation that could affect their participation in a self-management and education programme.

4.5.2.1. Attitudes

This section covers the attitudes of the participants towards their own health, their fellow community members as well as their compliance, which could be a reflection of their motivation to participate in any community related rehabilitation programmes. The participants were honest about their attitude towards their health and their risk taking behaviour even after they have been warned not to do certain activities anymore. This was confirmed by the focus groups who stated that the people know that they should eat healthy, but they just don't adhere to their diets. The participants however did disclose that the healthy food is too expensive for them:

"I do not know what he says anymore (the doctor), because it's not important to me."

(Participant 5; >20yrs)

"The problem actually lies with me, because I have never sought help. I'm not one to have my file pulled and tell the sisters, even if I have pain... I did receive an eating plan... [Laughing]... I can hardly eat anything on that plan. There's a lot of stuff one has to avoid."

(Participant 15; 1yr)

"The doctors already told me I should remember that I should not climb onto things. But if I don't who's going to do it?" **(Participant 12; >20yrs)**

"The stuff is too expensive. It cost too much what they have to use (healthy food)."

(Participant FG2)

It was evident that some participants were not taking ownership of their own health, missing appointments or not making enquiries during or after a consultation. This lack of buy in and ownership might be due to the gap in their knowledge regarding their own condition:

"I was supposed to go, but didn't." **(Participant 16; 13yrs)**

"She gave me another appointment, but I did not go because we had to arrange for ID's."

(Participant 6; 4yrs)

"Yes, but the doctor should have referred me and he did not refer me." **(Participant 3;**

>20yrs)

"She did not give me another appointment date (the physiotherapist)... I decided then that I'm not benefiting from going there (the clinic) because they are not giving me anything for it." **(Participant 18; 12yrs)**

The community health care workers confirmed the lack of ownership among the community members, and one particular participant in the focus group felt that the people were not as uninformed as they appear to be, and are impatient with things such as service delivery (waiting times at the clinic):

"So it depends on that person to take the responsibility for his own health and go to the clinic." **(Participant FG15)**

"Then they do not bother again. They just keep going with their disease [without going to doctor again]... They are not at all uninformed. I believe that they are being told, but it is just how people are." **(Participant FG16)**

"They do not ask again and do not go again... Uninformed. And impatient. This community is very impatient... Because the people are very impatient and ignorant, and not just with regards to arthritis, with everything health related." **(Participant FG17)**

As can be seen in figure 4:5, according to the demographic questionnaire, seven participants did not have a DVD player themselves, and stated that it is a luxury not everyone could afford. Only three participants had a smart phone which could be used with an App. Even though one focus group participant stated that a lot of people cannot read or write, only one participant were illiterate. Therefore a booklet with information would be best suited for the individuals of these communities.

4.5.2.2. *Social isolation*

This study also explored the psychological factors of the individuals such as their openness to new experiences and their self-confidence to attend a community-based intervention, however, these factors were not as prominent as expected. However, social isolation was seen in individuals who felt that their pain and impaired mobility did not encourage them to interact with their friends and family. This could be a barrier to accessing a self-management programme, especially if it is offered in a group setting and individuals do not feel comfortable leaving their homes and interact with other people:

"I don't leave the house anymore. I just sit there." (Participant 5; >20yrs)

"If I don't feel up to it then I don't go... I'm also not in the mood to see people." (Participant 11; 7yrs)

"You see, I don't walk anymore, and I don't go to visit people anymore... Now, no, it's too nerve-wracking. I can't do it anymore. Now I just sit at home." (Participant 10; >20yrs)

"My daughter lives down there. I used to walk to her every day. Not anymore. This year I am unable to walk so far." (Participant 12; >20yrs)

4.6.1. Summary

In summary, environmental and personal barriers to a community-based self-management intervention have been identified. The environmental factors related to the service delivery, transport and security within the environment which could affect the accessibility of a self-management programme. Some concerns were raised with regards to the community attitudes and social division that could influence the participation of individuals. Negative attitudes towards possible group leaders (CHCW, physiotherapist and peer leader) for the presentation of the programme should be taken into consideration, as it could influence the willingness to partake in such a programme. The mode of information delivery were also explored and technological barriers such as the use of a DVD, the internet or a cellular phone was identified as current factors that could influence adherence to the programme. In addition, some personal barriers were also identified and included the individuals' attitude towards their own health as well as their compliance and ownership that could reduce their

participation. Finally, social isolation were also a key concern raised, as individuals might not participate if they feel discouraged by their pain and functional limitations.

4.6. Objective 4: Self-management implementation facilitators

The positive contextual factors were also discussed with regards to the implementation of a self-management and education programme. The facilitators of such a programme within these communities were divided between environmental and personal factors as demonstrated in the table below 4:4:

Table 4:3 Self-management implementation facilitators

Environmental factors		Personal factors	
<i>Venue</i>	<ul style="list-style-type: none"> · Clinic and public spaces 	<i>Motivation</i>	<ul style="list-style-type: none"> · Interest · Optimism · Strategies
<i>Support</i>	<ul style="list-style-type: none"> · Community support · Family support · Current groups · Health care support · Alternative pain management strategies 	<i>Group leader</i>	<ul style="list-style-type: none"> · Community champion

4.6.1. Environmental factors

Environmental factors that could facilitate the implementation of a self-management and education programme were found to be the venue and the support systems within the communities.

4.6.1.1. Venue

Central locations seems to be the best option for most of the people in the communities, and many of the participants stated that the clinic is the best place for a group to meet and exercise. Some of the other options mentioned was the community hall or the church. The PI noticed that all of the communities had a library, which could be a viable option for self-management information sessions.

"(The clinic) is the best place, yes." (Participant 15; 1yr)

"Central remains the best option, yes." (Participant 16; 13yrs)

4.6.1.2. Support

Support from the environment comes in the form of their immediate family as well as their friends, neighbours and the health care personnel.

i. Community support

A majority of the participants expressed that they get along with their neighbours and believed that the people in the community can support one another. This was confirmed by the focus groups who stated that people do care for one another and will spread the word if they felt that the self-management programme is helping them. It was also felt that people with the same condition will support one another:

"I think they would support each other because they have the same problem... We'll be able to give each other advice which may solve a problem." (Participant 9; >20yrs)

"We get on well with our neighbours and everybody knows everyone." (Participant 15; 1yr)

"If I know this works for me, then I would definitely tell you to come with me, because it works for me." (Participant FG15)

ii. Family support

There were no shortcoming in the amount of family support expressed by the participants. Most of them receive unconditional support from the family members within their home, the community and beyond:

"Fortunately my children are very supportive. My daughter who looks after me at home, because I don't have a wife, she would say, Dadda must say if I need to wash your back, then they will help. Especially my daughter who still lives with me. She is always happy to help me." (Participant 9; >20yrs)

"Yes, you must go with. And if I have this problem and I am struggling. My neighbour knows I really want to be there, but she does not have that problem, she will help me get there, or my cousin will come and take me. So the family support are there." (Participant FG17)

iii. Current groups

Some of the participants recollected being part of an exercise group before, and stated that it was a great support network for them. One of the communities currently have a diabetic and drug group which is being run by the nursing staff with great success:

"We would talk about our problems, not about other people, just your own problems. And then we sit and chat. But we would encourage one another. It was nice." (Participant 7; >20yrs)

"Here we have a diabetic group run by Sister L... they meet here at the clinic every Monday. So I think it will work if we create something like this." (Participant 15; 1yr)

iv. Health care support

Support from the health care comes from the staff at the clinic as well as the community health care workers. The majority of the participants thought that the sisters at the clinic gave them good support. This was confirmed by the focus groups as some of the CHCW recollected their experiences of being a patient at their local PHC facilities. Some of them even had arthritis and stated that they were satisfied with the service from the nursing staff at the clinic:

"I know I had an arthritis case, I talk out of personal experience now, and the clinic informed me very well of the condition." (Participant FG17)

"And like they explained to me, arthritis is a diagnosis, and it has symptoms, but it does not have a treatment." (Participant FG18)

"And she also said it is a lifestyle, because your lifestyle has to change, then your arthritis attacks will be less." (Participant FG19)

The focus groups confirmed that they offer their support whenever they can and also mentioned that they try to inform people on their diet when required. The CHCW's also stated that they provided exercises to the community members in the past. However, due to a change in their scope of practice they are only allowed to give guidance on exercises if they receive a referral from the clinic.

"Especially if we see that there is a problem with weight or pain or that sort of thing, then we would encourage the person, the less you weigh the less weight there is on the painful area. Foot or knee or so, and that helps a lot." (**Participant FG19**)

"There was a time when we gave those exercises to the people ourselves." (**Participants FG17**)

At one of the areas that were visited, a student exchange programme with the Netherlands were in process, where physiotherapy and dietetic students were working with the people in the communities. They focused on education and physical activity, and the feedback received from the community members were positive all round. Programmes such as these might be an opportunity for non-profit organisations to assist in filling the health care gaps in the communities.

v. *Alternative pain management strategies (Boererate)*

The conversation about alternative symptom management mostly took place within the focus groups, as the participants with knee OA did not disclose this information when they were interviewed, except one lady who stated that she drank some form of herbal water. This information was always shared spontaneously by the community health care workers when asked what the people received as treatment for their knee OA and their pain. Some of the CHCW stated that they have tried these themselves, and that it worked.

The illustration 4:6 below demonstrates all the alternative ways in which the people in the communities managed their symptoms with advice from their elderly and were viewed as support and advice provided by their community members and families. These remedies were present in all the communities visited.

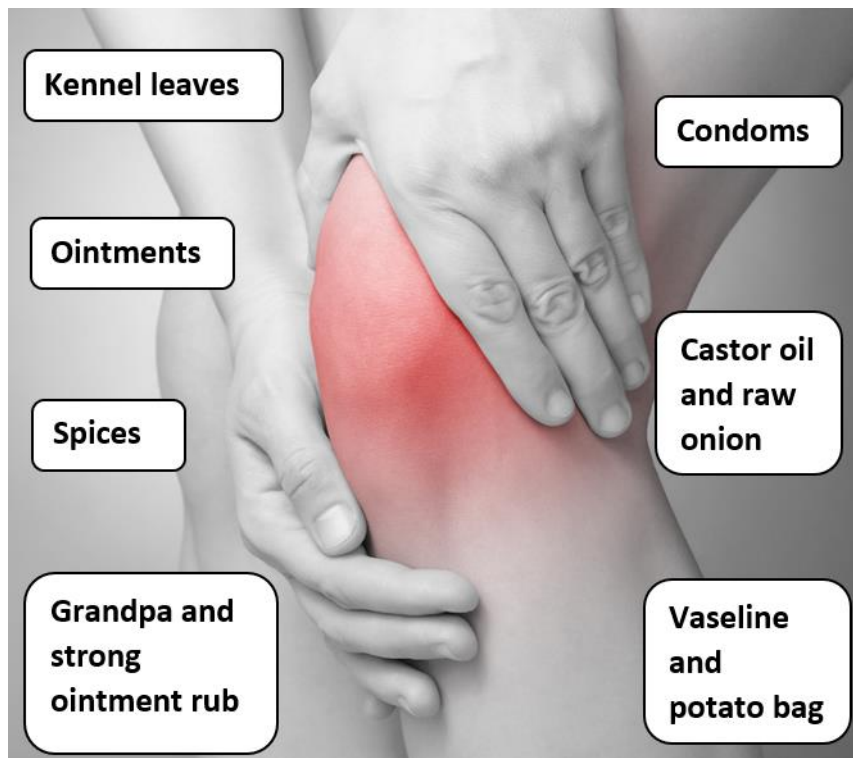


Figure 4:7 Alternative pain management strategies (adapted from Dyer, n.d.)

Most of the remedies are external “rub on” remedies where they use different ointments and mixtures to relieve the pain. Some of the products are store bought pain relief products while others were homemade. Some of the remedies were related to consumption of products that were mixed or boiled together such as herbs and spices. The people also used the lubricant of condoms to rub it on the painful area, and at times they put the condom over the painful joint (such as the foot or hand) to relieve the pain. It is an integral part of their culture and were used as an adjunct to their prescribed medication:

“Our people use condoms these days, that silicone. They say it works.” (Participant FG5)

“Then they take the inside of a bag of potatoes, that pale paper. Then they rub Vaseline on it, thick. Then they put that onto themselves and they say it brings about relief.” (Participant FG8)

4.6.2. Personal factors

These were the factors that demonstrated the individuals' motivation to take part in a self-management and education programme. These are ultimately the most important when considering the contextual factors for implementation, as the individual has to be the driving force for their own self-management.

4.6.2.1. *Motivation*

Motivation speaks to their display of interest and optimism in being part of a self-management and education programme. It was also demonstrated by the adaptations they have already made in their life, showing their determination to improve their own situation.

i. Interest

Most of the participants stated that they themselves would participate in a self-management programme, and were sure other members of the community would be interested too. The focus groups confirmed this and stated that the people will be interested, especially if it is for the benefit of their own health:

"It will work. You must give the information to the people at church so that it can be announced in church... Then there are many people. I think they would be interested. I will also put a hop and skip in my step and walk up here." (Participant 10; >20yrs)

"Yes, if you invite a group of people with the same disease, then I do think the people will be interested and appreciate the support they will get." (Participant FG17)

ii. Optimism

The majority of the participants were optimistic about the idea of a self-management programme and stated that they believe such a programme would help them very much. They also spoke about their own exercise habits that they used to have, which is a statement of their motivation:

"It's a good idea, yes. I always used to do the exercises that were shown on television at five o'clock in the morning." (Participant 14; >20yrs)

"I will give my support and if he tells me do this or that or I must do it like this, then will do it because I want to be helped." (Participant 9; >20yrs)

"And if they will benefit from that and there will be an improvement for their own health, they I believe they will participate." (Participant FG5)

iii. Strategies

During the interviews, the majority of the participants revealed their motivation by talking about the adaptations they have made and the strategies they have adopted in their life to be able to continue doing the things that are important to them.

"I did my work and would then rest a little or go and lie down and then continue with my work." (Participant 3; >3yrs)

"I still do everything. I wash my carpet myself now. I lie on my side first to get on my knees. When I've made some progress and I feel my knees have had it, then I lie on my side again." (Participant 14; >20yrs)

"Yes sister. But I did not have the surgery yet. Even by dragging the leg I kept on struggling to plant a pip and got pumpkins." (Participant 7; >20yrs)

4.6.2.2. Group leader

The majority of the participants were open to the idea of having the self-management group being run by the community health care workers or even a fellow trained community member with knee OA. The focus groups were mostly positive in their response to being possible group leaders, as they are eager to know more about the condition themselves and to be of assistance to their fellow community members.

However, it was mentioned multiple times that the people with knee OA in the community must choose the leader themselves, as this could influence the participation of the individuals:

"Yes, they can decide for themselves. We could decide as a group who may be the most suitable candidate to get the training." (Participant 15; 1yr)

“See, I would suggest that you bring everyone together and then see who would be willing and then out of that group appoint a person as a leader.” (Participant FG16)

4.6.3. Summary

In summary, the facilitating factors that could aid in the implementation of a self-management programme included environmental and personal factors. The support from their families, the community and the health care providers were identified as prominent facilitators which could encourage participation. Personal factors included the interest and optimism that were displayed by the participants during the interviews. In addition, the openness to new strategies and the current use of alternative pain management strategies (“boererate”) could prove valuable during the implementation of a self-management programme.

4.7. Chapter summary

The current services offered to individuals with knee OA in the rural areas of the Western Cape where predominantly focussed on the pharmacological pain management, and lacked sufficient information and education. Physiotherapy services were underutilised and rehabilitation were not seen as an important component in the management of symptoms. The participants expressed their need for knowledge on the condition and to receive comprehensive treatment from their PHC facility. The concept of a self-management programme for knee OA in their community were explored and contextual barriers and facilitators were identified. The barriers included attitudinal, financial and service related factors that could influence the participation and adherence to a self-management programme. Facilitating factors were related to the support received from their family, friends and the nursing staff at the PHC facilities. Participants were optimistic and open to new interventions that could improve the management of their knee OA and ultimately their quality of life. The following chapter will discuss the main findings of the study as well as the significance of the results within the context of current literature.

Chapter 5

Discussion

5.1. Introduction

This chapter contains a detailed discussion based on the results presented in Chapter Four. The data will be compared to other relevant literature and the significance of the findings will be explored.

5.2. Main aim and findings

The aim of this study is to describe the contextual factors that could influence the implementation of a self-management and education programme for people with knee osteoarthritis (OA) living in the rural settings of the Western Cape, South Africa. In addition, the current services offered to these individuals were explored along with their rehabilitation needs.

The main findings of this study showed that the treatment offered to patients with knee OA in the rural settings of the Western Cape are not optimal when compared to available clinical practice guidelines on the management of knee OA (Fernandes, Hagen, Bijlsma, Andreassen, Christensen, Conaghan *et al.*, 2013; Meneses *et al.*, 2016). Nonetheless, the needs identified in these settings were comparable to the components of a self-management and education programme. Therefore, a self-management and education programme as discussed in the current literature would be the ideal solution to address the needs of these individuals (Hochberg, Altman, April, Benkhalti, Guyatt, McGowan *et al.*, 2012; Fernandes, Hagen, Bijlsma, Andreassen, Christensen, Conaghan *et al.*, 2013; McAlindon, Bannuru, Sullivan, Arden, Berenbaum, Bierma-Zeinstra *et al.*, 2014; Glyn-Jones, Palmer, Agricola, Price, Vincent, Weinans *et al.*, 2015; Kruger-Jakins *et al.*, 2016). Some contextual factors should however be considered when planning the implementation of such a programme in these areas. Personal factors such as ownership, compliance and social isolation could influence their long term commitment to a self-management intervention. In addition, environmental factors such as the community attitudes and available transport which could have an impact on their motivation and attendance. These factors are discussed and compared with literature in the chapter below.

5.3. Rehabilitation services currently received by people with knee OA in the rural areas of the Western Cape

When considering the management of knee OA, the current clinical practice guidelines suggest that when the individual is diagnosed with OA, they should receive three core treatments from their health care provider. These core treatments essentially consists of education, exercises and weight loss therapy (if required) (Conaghan *et al.*, 2008; Hochberg *et al.*, 2012; Nelson *et al.*, 2014; Glyn-Jones *et al.*, 2015). This study found that in accordance with the clinical practice guidelines, the current health care services offered to people with knee OA living in rural parts of the Western Cape includes exercise guidance, education and weight loss advice. However, these services were only offered to the minority of the participants and were inconsistent and varied greatly in content and depth. In addition, the most prominent service offered was pharmacological pain management at the primary health care (PHC) level. These findings were consistent with the findings of a low back pain study done by Major-Helsloot *et al* (2014) who found that 90% of patients received pain medication as the only form of treatment from the PHC system, which would suggest that the system is not equipped or informed about any alternative pain management strategies, regardless of the condition.

In the ideal circumstances, the core services would be delivered by a multidisciplinary team (MDT) including the doctor, nurse, physiotherapist, occupational therapist and dietician, all focussing on their respective areas of expertise. However, the PHC system in South Africa, especially in the rural areas are not equipped with full time multidisciplinary teams, and patients are often only seen by one or two of the members in the MDT (Bateman, 2012; Lalkhen & Mash, 2015). However, this should not be a significant barrier as the core services can be delivered by any of the members of the MDT to some extent, until further referral can be made. In this study, it was often seen that the core service delivery was dependant on the nursing staff and the doctor, with occasional referral and involvement of the physiotherapist. Without the explicit involvement of the physiotherapist, exercise was delivered in the form of guidance and advice to stay active and walk often, rather than a formal exercise programme from the doctor and the nurse. Nonetheless, an Ottawa panel review on the recommendations of strengthening and aerobic exercise programmes found that, any form of exercise seems to improve at least one of the key outcomes (pain, function or quality of life) when compared to controls (Brosseau, Taki, Desjardins, Thevenot, Fransen, Wells *et al.*, 2017).

Some participants received physiotherapy at some point, however, frequent follow up or sessions extending beyond the first contact were scarce. This could be due to resource constraints of the PHC system which only

allows the physiotherapist to visit a rural area once a month, or the poor referral structure within the health care system (Bateman, 2012; Dookie & Singh, 2012; Major-Helsloot *et al.*, 2014). Although the lack of professional exercise prescription is unfortunate, the general advice appears to have been taken seriously by some, even if the importance of exercise as a core form of treatment was not known to the participants. In addition, even though the majority of the areas in the study had a visiting dietician, only one participant reported having had a consultation. The remaining participants received their dietary advice from the doctor. This is a concern because the patients could have received more comprehensive treatment by the various members of the multi-disciplinary team (MDT), each being a specialist in their area. Concurrently, previous studies have found high rates of referral to orthopaedic surgeons, often without having consulted alternative treatment options (Brand, Harrison, Tropea, Hinman, Britt & Bennell, 2014; Thorstensson *et al.*, 2015). Similarly, this study found that doctors at the PHC facilities often referred patients for corticosteroid injections and possible surgical management, even though the injections only provided temporary relief to the patients. The lack of referral has been attributed to the beliefs and attitude of the doctor attending to the patient. If the doctor felt that they provide sufficient care and the specific referred service would not add any additional benefit (such as dietary advice from a dietician being no different from their own advice), they were reluctant to refer (Ampt, Amoroso, Harris, McKenzie, Rose & Taggart, 2009; Cottrell, Roddy & Foster, 2010). An additional barrier to referral was their lack of familiarity with the services or benefits offered by allied health professionals. Therefore it could be recommended that doctors receive education on the specific role of each member within the multi-disciplinary team to improve their awareness of services and the extent of their role in patient care.

The participants in this study also gave varying views on the amount of information they have received from their health care provider, and the principle investigator (PI) had to prompt for specific categories of information that were covered. In accordance with a survey done on the South African PHC system, all the participants in this study were seen by the nursing staff at the clinic for their knee OA, after which 87.5% of them were referred to the doctor for further management. This referral rate was almost three times the usual rate (33.1%) of patients with non-communicable diseases who get to see the doctor according to the survey done by Mash *et al.*, (2012). Interestingly, the participants recalled their information sessions with their doctor more often than sessions with the nursing staff or any other rehabilitation professionals, which emphasizes the important role of the doctor in the life of the patient (Tofan, Bodolica & Spraggon, 2013). However, it may also elude to the fact that patients typically regard the opinion of a doctor higher than that of other health professionals. This is a potential issue in areas where doctors are not available as often, and patients are mostly consulted by the

nursing staff. It could therefore be recommended that a shift in patient education be made with an emphasis on the equally important roles of each health professional.

5.4. Rehabilitation needs of people living with knee OA in rural Western Cape

"I only want to receive good treatment." (Participant 9; >20yrs)

When asked if the treatment they currently receive are helping them, the majority of the participants responded that it did not help them and that they feel they are not receiving sufficient or appropriate treatment for their knee OA. This is in accordance with studies done in South Africa and Uganda as well as in developed countries such as Canada and Europe where patients felt that they are not receiving adequate care for their musculoskeletal conditions from their health care practitioners (Selman, Higginson, Agupio, Dinat, Downing, Gwyther *et al.*, 2009; Osterås *et al.*, 2013; Major-Helsloot *et al.*, 2014; Ali, Walsh & Kloseck, 2018). The rehabilitation needs that were evident from the study included education, exercise, improved mobility and coping mechanisms. These needs are typically addressed by a rehabilitation professional such as a physiotherapist, however, it is within the scope of practice of any member of the multidisciplinary team (nurse, doctor, occupational therapist etc.) to address most of the basic needs and make the appropriate referrals.

According to literature, the ability to manage a progressive disorder and to function in one's daily life is directly affected by the knowledge and insight one has about the condition (Selman *et al.*, 2009; Aws, Nüesch, Sterchi, Kalichman, Hendriks, Osiri *et al.*, 2010). Information and knowledge has the capacity to reduce your pain, improve compliance with exercise and most importantly, it could improve your health seeking behaviour (Brosseau *et al.*, 2010; Mann & Gooberman-Hill, 2011; Cobbing, Hanass-Hancock & Deane, 2014). These were all components that were affected in the lives of the participants in this study, which could be attributed to their lack of knowledge on their condition. Similarly to this study, a report from Uganda stated that patients did not receive sufficient information and at times the only knowledge the person had was obtained through a magazine article or a family member/ friend, which could lead to misconceptions and myths (Selman *et al.*, 2009; Ali *et al.*, 2018).

However, it has been found that doctors also lack the specific knowledge on the condition which could contribute to misconceptions and therefore not encourage lifestyle changes or health seeking behaviour in their patients (Clarson, Nicholl, Bishop, Edwards, Daniel & Mallen, 2013; Osterås *et al.*, 2013; Spitaels,

Vankrunkelsven, Desfosses, Luyten, Verschueren, Van Assche *et al.*, 2017; Ali *et al.*, 2018). This is possibly amplified by the lack of time the doctor/ nurse has with the patient due to the high patient load in the PHC facilities, which in turn reveals the failure of the system and does not necessarily speak to the incompetence of individual health care practitioners (Selman *et al.*, 2009; Bateman, 2012; Cobbing *et al.*, 2014; Major-Helsloot *et al.*, 2014). Although, it has been documented in Europe that doctors find the lack of reimbursement and patient adherence/ motivation to be a major barrier to their decision to discuss lifestyle changes with their patients (Clarson *et al.*, 2013). Additionally, Selman *et al.* (2009) reported that some people prefer to know as little as possible about their condition, which could influence the doctors' decision to disclose information. However, all the participants in this study felt that they would benefit from knowing more and were therefore open to receiving information. The effect of not having sufficient information appeared to contribute to feelings of anxiety and the participants' ability to manage their condition optimally, as described by Selman *et al.* (2009). In addition, Dube *et al.* (2017) found that nursing staff in a South African township lacked the educational material they desired and had no structured plan for self-management education on non-communicable diseases. This led to conflicting and disorganised information that was shared with the patients, creating misconceptions and confusion.

Furthermore, some of the participants felt that they did not receive the personal attention they desired from their health care practitioner during the consultation, which gave the sense that they feel they were not being heard. Other authors offered possible explanations for the lack of attention and stated that their participants felt that the consultation with their doctor and nurse were rushed and that OA was not seen as a priority within the clinic (Selman *et al.*, 2009; Spitaels *et al.*, 2017; Ali *et al.*, 2018). In addition, they stated that the communication abilities of the clinic staff deteriorate when they are working under pressure. Another viewpoint was that doctors often have a paternalistic approach in their care and patients are not empowered to participate in the conversation, which could leave the patient with information they do not understand and unanswered questions (Selman *et al.*, 2009; Edwards, Wood, Davies & Edwards, 2012). Ineffective communication from the health care practitioner and a viewpoint that OA is not a priority would not encourage productive health seeking behaviour from the individual, leaving that person discouraged and perhaps isolated.

In addition to information/ education, exercise and strengthening are important in reducing progression of the disease and maintaining biomechanical integrity of the joint (Nelson, 2018; Thorstensson *et al.*, 2015; Brosseau *et al.*, 2017). Exercise and strengthening also helps to reduce pain, improve function and general fitness in people with knee OA, which addresses the negative effects of a sedentary lifestyles that is often

adopted by people with knee OA as a result of pain and functional limitations (Saw *et al.*, 2016; Brosseau, *et al.*, 2017). All but one participant in this study did not follow an exercise programme, and was not aware of the benefits of exercise for the management of knee OA. This is possibly due to common misconceptions that exercise might cause harm in the affected joint, or that it has no benefit to the patient, which is a view that has been shared by some physiotherapists (Thorstensson *et al.*, 2015). The lack of physiotherapy involvement for participants of this study is most likely one of the main contributing factors to the lack of exercise management amongst these individuals. Even though a few participants attended physiotherapy in the past and received a home programme, they stated that they did not follow it anymore, which highlights the issue of compliance in an exercise programme and motivation for behavioural change related to chronic disease management (Thorstensson *et al.*, 2015; Brosseau *et al.*, 2017).

Similar to other studies in South Africa, the shortcomings of the PHC system affected the participants in this study as well. They expressed their frustrations with long waiting times, the shortage of medication and the communication issues with the staff at the clinic which are just some of the well known concerns within the system (Selman *et al.*, 2009; Dookie & Singh, 2012; Visagie & Schneider, 2014). The lack of client-centred care left the health care users with a somewhat negative attitude towards the PHC system, and discouraged them to seek further medical attention. Visagie *et al.* (2014) attempted to gain clarity from the insight of the health care providers, and found that the doctors and nurses themselves had frustrations with the system that did not allow them flexibility in decision-making and were not always user friendly. In addition, they also felt that they are not always equipped to handle complex situations and are not experts in all the topics of health care and did not receive support (Visagie & Schneider, 2014; Lalkhen & Mash, 2015). Nonetheless, that does not account for patients not being included in the decision-making process, which is still an unfortunate reality of the current health care system as patients are entitled to have their preferences, concerns and goals heard (Lalkhen & Mash, 2015). However, contrasting views were offered by the focus groups who felt that the service offered by the primary health care system is free and that the people in the community should not complain about the shortcomings. This was echoed in another study which found that some community members are “reflexive and reactive”, with minimal expectations from the system and felt that even though not all of their needs are addressed, they are still appreciative of the services (Selman *et al.*, 2009).

Considering that the majority of needs expressed in this study related to the lack of information and understanding in the management of their condition, a self-management programme as described by the

current clinical practice guidelines should be considered as the ideal solution to address the needs of the individuals with knee OA living in the rural areas of the Western Cape.

5.5. Self-management as a solution to address the specific health care needs

As described by Conaghan *et al.* (2008), the National Institute for Health and Clinical Excellence (NICE) guidelines on OA suggest that every patient with OA should receive education and advice regarding their condition, strengthening and aerobic exercises and if required, a weight loss programme. However, as described earlier, in this study and others alike, these core treatment are not fully covered in the consultation sessions that the patients have with their health care providers and a gap exists between the recommendations and the clinical application (Dziedzic, Healey, Porcheret, Ong, Main, Jordan *et al.*, 2014; Healey, Afolabi, Lewis, Edwards, Jordan, Finney *et al.*, 2018). Considering that OA is a lifelong condition, self-management has an important role in the life of the patient and the ability of the patient to manage their condition is dependent on their knowledge and the information they receive about the condition (Hurley & Walsh, 2009; Ali *et al.*, 2018). Therefore, self-management programmes have been developed to empower patients and equip them with a better understanding of their condition, containing the key aspects of care as recommended by the prominent CPGs (as discussed in section 2.3.3) and to teach patients the skills required to manage their symptoms effectively (Hurley *et al.*, 2012; Thorstensson *et al.*, 2015; Kruger-Jakins *et al.*, 2016). However, Heyns (2018) found that CPGs lack detail in their description of content and context, and are subsequently difficult to reproduce. It was therefore recommended that the contextual factors of these CPG's be explored in to improve the reproducibility and implementation.

A common approach has been a six week programme that constitutes six one/two hour sessions which cover all the required content in relation to the condition, an exercise programme, weight management and coping strategies, such as the programme developed and used at a tertiary hospital in the Western Cape, South Africa for patients awaiting knee arthroplasty (Kruger-Jakins *et al.*, 2016). The content of these sessions were informed by other programmes for chronic disease management, such as the Chronic Disease Self-Management Programme (CDSMP) developed by the Stanford School of Medicine (2018) as well as CPGs and the RCT's that were used to formulate the clinical guidelines. Variations of self-management programmes have been developed over the years with some similarities and differences in the presentation, content, duration, frequency, follow-up etc. The differences of interest to this particular study, are the presentation of

the programme in a group versus on an individual level, if the programme is led by a physiotherapist versus led by a trained lay person and frequency of presentation.

Fransen *et al.* (2015) stated that individual exercise with a rehabilitation professional has a larger effect than group or home exercise programmes. In addition, Thorstensson *et al.* (2006) stated that patients found value in their individual contact with a physiotherapist who can supervise their exercises and follow-up on their progress. Most self-management programmes are developed to be presented by a physiotherapist, who is the rehabilitation expert that usually gives information to the patient and prescribes their exercise regimen. However, in rural settings where the physiotherapist visits the community once a month and would not have time to treat all of the acute conditions in the community as well as the chronic musculoskeletal conditions individually, a group intervention is an alternative option that could have benefits for the patient as well as the physiotherapist. Not only would the group intervention save time, it would also have the benefit of encouraging social networking between the individuals with the same condition. The social interaction could assist those who isolate themselves due to the condition to interact with other members of their community as well as form a platform to share their experiences and remedies within a social network (Ali *et al.*, 2018). This peer support system could be of great value to individuals who are suffering from a chronic condition such as OA, and could improve the participation and sustainability of a community-based intervention (Lauckner & Hutchinson, 2016)

Unfortunately, one of the disadvantages of a group intervention is the reduced capacity for individualised information and exercises, which could affect the efficacy of the programme (Selman *et al.*, 2009; Fernandes *et al.*, 2013; Thorstensson *et al.*, 2015). In previous studies, individuals who received personalised information had an improved recollection when compared to general information (McPherson, Higginson & Hearn, 2001). However, even though there has been controversy in the literature on the superiority of a tailored information and exercises programme versus a general programme, most authors found that there is a benefit to any form of information and exercise when compared to no information or exercise at all (Delarue, de Branche, Anract, Revel & Rannou, 2007; Tiffreau, Mulleman, Coudeyre, Lefevre-Colau, Revel & Rannou, 2007; Selman *et al.*, 2009; Brosseau *et al.*, 2017). Ideally, there should be consistency and frequent follow up, especially if the programme includes an exercise component. Multiple studies have found that exercise for knee OA is more beneficial in reducing pain, improving function and increasing quality of life, if performed on a regular basis (Brosseau *et al.*, 2017). Therefore, it could be considered that the group meet more often than once a month, and a lay group leader should be trained and appointed to assist in continuity of care, especially in the context

of professional staff shortages (Selman *et al.*, 2009; Ali *et al.*, 2018; Angwenyi *et al.*, 2018). In addition, variations in self-management programmes also included the mode of information delivery which comprised technology such as CD's and web-based training and also assumed a level of literacy from the individuals with workbooks and information leaflets (Heyns, 2018).

It is evident that self-management is not an isolated occurrence and various personal and environmental factors affects an individuals' ability to implement these strategies (Angwenyi *et al.*, 2018). Considering all the components influencing a self-management programme, it is therefore encouraged to explore the contextual barriers and facilitators to implementing a self-management programme in the specific area. Obtaining contextual information would assist in tailoring the programme to the needs of the community before implementation (Grut *et al.*, 2012; Waiswa, Namazzi, Kerber & Peterson, 2015; Burrell, Jordan, Crowe, Wilkinson, Jones, Harris *et al.*, 2018; Heyns, 2018). The following two sections will explore the barriers and facilitators identified in the rural areas of the Western Cape in relation to a group as well as an individual intervention.

5.6. Contextual factors related to the implementation of a self-management and education programme in the rural areas of the Western Cape

Over the past two decades, health research has been re-focussed to consider the social determinants of health care and the effect of an individual's socioeconomic situation on their health outcomes (Luong, Cleveland, Nyrop & Callahan, 2012; Sherry, 2015). According to the international classification of function (ICF), the individuals' contextual factors (personal and environmental) are the primary indicator for reaching rehabilitation goals (WHO, 2002). This is particularly true for individuals living in rural areas, who are affected by various social, financial, structural and service delivery constraints, often leading to a cycle of poverty and disability (Luong *et al.*, 2012; Department of Health, 2015; Sherry, 2015).

When considering the factors that could affect the implementation of a self-management programme in a specific community, one has to consider the social determinants of that specific area, which will contextualize the factors affecting health care access adherence. The prominent contextual barriers and facilitators of this study were divided between environmental and personal factors.

In accordance with multiple other publications, service delivery was described as a major barrier to accessing health care regularly (Selman *et al.*, 2009; Major-Helsloot *et al.*, 2014). The specific service-related barriers within the contexts of this study were related to safety of the environment, transport and continuity of care (section 4.5.1). Neillie & Penn. (2015) described how violence and safety problems have influenced the access of services for people with disabilities in rural areas in Mpumalanga, South Africa. Although the violence and safety issues within this study was not as severe as described by Neillie & Penn (2015), it will influence the time of day and the venue for a group self-management programme. For both an individual and group self-management programmes, transport would be a barrier for those who live on the outskirts of the town and are unable to walk far distances as were reiterated by the participants of this study (section 4.5.1.1.ii). Transport issues are also a known barrier to accessing health care in rural areas, and contribute to the financial demise of the patient, as the available transport is expensive (Grut *et al.*, 2012; Cobbing *et al.*, 2014; Visagie & Schneider, 2014; Sherry, 2015). Therefore, a central location has to be identified for delivery of a group intervention. However, as was discovered in this study, most venues are not free and require a payment if it is used by the community. Alternatively, the clinic is available, but is usually too small to accommodate a large group and would be more suited for individual treatment. It might be necessary to network with community stakeholders who could assist in identifying alternative solutions, as suggested when taking a Community-based Rehabilitation approach (WHO, 2010).

According to Visagie *et al.* (2014), a small rural community is usually supportive and tight-knit on a social level, which was found to be true in two of the areas that were visited in this study. However, a social division related to multiple personal and environmental factors were noted in one of the areas. These factors included a religious and political divide within the community, especially amongst the elderly. The most prominent divide however was related to scarce casual job opportunities from the local municipality, which created a competitive atmosphere as there was not nearly enough work for the amount of people that were unemployed. A social division such as this could therefore result in lack of participation in a social group setting. Alternatively, it is also possible that a community based group intervention could improve the cohesion as a result of the peer support, influencing health and social behaviour (Martin & Dimatteo, 2014). However, this is beyond the scope of this study.

In addition, the social isolation reported by the participants of this study are a concern for their participation in a self-management programme. It was stated that their impaired mobility and general transport issues kept them from visiting friends and family who did not live close to them. Some of the participants also stated that

they do not feel like visiting friends due to the pain, and that that they prefer to stay at home. Social isolation is known among people with chronic pain, influencing their participation in social and community related activities (Schulman-Green, Jaser, Park & Whittemore, 2016; Makris, Higashi, Marks, Fraenkel, Gill, Friedly *et al.*, 2017; Wylde, Beswick, Bruce, Blom, Howells & Gooberman-Hill, 2018).

Continuity of care has also been highlighted as a known barrier to service delivery and building relationships with patients (Wong & Regan, 2009; Dookie & Singh, 2012; Mahomed, Asmall & Freeman, 2014). Similarly, in this study, the participants were concerned for the continuity of a self-management programme if it is led by the physiotherapist who they feel does not have time for an intervention such as this. In addition, if this programme was led by a trained lay person from the community, the participants felt that without compensation the trained person might not be reliable in their continued delivery of the programme. This was also mentioned in an article by Lauckner & Hutchinson (2016) that incentives such as payment, rewards and acknowledgement were important aspects for continuity in peer leader programmes.

Another concern were related to personal factors such as the individual's attitude towards their health, as some individuals did not demonstrate the correct health seeking behaviour. This is often influenced by a lack of knowledge, which in part could be due to the lack of information given to the patient during consultation. However, it might also be due to the general lower level of education often seen in individuals living in rural areas, which related to their poor socioeconomic situation (Neillie & Penn, 2015; Sherry, 2015). System shortcomings such as long waiting times at the clinic, lack of transport and financial cost, could also affect the persons determination to seek health management (Angwenyi *et al.*, 2018). This could be seen in the observation made by the focus group stating that the people in the community are impatient to wait in line for their medical care (section 4.5.2.1). Their health seeking behaviour could also be influenced by the general perception that OA is a normal part of ageing with no cure. This belief is reinforced by the general lack of patient centred care where doctors tell patients that nothing can be done and providing pain medication as the only form of treatment (Visagie & Schneider, 2014; Ali *et al.*, 2018). All of these factors could also explain why the focus groups felt that the community members did not take ownership for their health and do not comply with their treatment. This could be seen in their reluctance to attend appointments, re-schedule missed appointments or return for follow up appointments after only one session (section 4.5.2.1). It should however also be considered that the information they receive from the medical staff may not have been relevant for implementation in their own situation. It is therefore important that information provided are specifically tailored to their context and appropriate for their implementation. However, previous studies have found that elderly

people made minimal use of health care services in the South African context when compared to neighbouring countries (Gómez-Olivé *et al.*, 2013). This was linked to poor awareness of chronic conditions as well as medication that is only given one month at a time, which could affect their adherence.

A related concern was raised by the focus groups, who felt that people will not attend a self-management programme if it is held too often. Once or twice a month was recommended. This was interesting as all but one participant was unemployed or a pensioner, and arguably could attend a community support group on a weekly basis. Frequency is however important when considering exercise, as the benefits on pain and function is minimal when not performed regularly (Tiffreau *et al.*, 2007; Brosseau *et al.*, 2017). Therefore, the self-management intervention should include a home exercise component, empowering the individuals to continue with their exercises on a daily basis.

Although Christensen *et al.* (2007) found that even a small reduction in weight could decrease the effects of disability on knee OA, addressing healthy eating habits might pose a challenge in the rural context. The focus groups in this study stated that even though the people are aware of healthy diets, they often opt for the unhealthy options which are less expensive and easier to find in their local shops. Similarly, a study that was done in Malawi found that the people in rural areas cannot afford healthy diets and will eat what is available and affordable (Angwenyi *et al.*, 2018). Additional barriers were seen in a study by Dube *et al.*, (2017), where participants felt that offence was taken when they did not eat the food a family or community members served them. A possible solution could involve the referral to a dietician who could assist in area specific recommendations for affordable and attainable food sources. However, if the dietician is not available, community programmes such as fruit and vegetable gardens could assist in providing healthier food options to the community.

Even though there are barriers that were identified, there were also themes that emerged which were indicative of the positive aspects within these rural communities that could assist with the implementation of self-management programmes. Environmental factors that were facilitators within these communities, were the support from the families and community members that were experienced by most of the participants, as well as the focus groups. Family and peer support are essential components in assisting with continued behavioural change, as they play an important role within the life experiences of the patient. As described by Angwenyi *et al.* (2018), successful management strategies are usually learned through observation and information of peers who have similar experiences. In addition, most of the participants felt that they received very good support

from the health care staff at the clinic (mainly the nurses), even though they did not receive adequate information. It was apparent that the nursing staff made an effort to support all the members in the community despite their own shortcomings. One of the communities had a diabetes and a drug support group which was organized by the head nurse at the PHC facility, and has been reported as a great success by the patients and focus groups. This was inspiring to all the other members within the community, as they thought that an arthritis group would attract many people in the community and could be a sustainable project. This view was based on their past experiences within their community and support group attendance. However, in contrast, the other two areas expressed how previous social groups within their community has failed, and that it was possible that a support group might suffer the same demise. Nonetheless, some people were optimistic that when the intervention was for the benefit of their own health, people within the community would participate and it could be a success. This was reflected by their motivation and desperation to try new interventions and to improve their knowledge and skills, similarly found by (Ali *et al.*, 2018).

Although most of the participants were willing to try exercise, they appeared unsure of this form of intervention. Similar findings were seen in a study by (Thorstensson *et al.*, 2006) who also stated that experiencing the benefits of exercise on their function and pain is not enough to keep patients motivated to do their exercises. This could be related to the belief that exercise will not cure the disease, and therefore it is not worth spending time doing, similarly found by Schulman-Green *et al.* (2015). This viewpoint was highlighted by a participant on why people might not be motivated to attend a group programme. In addition, exercise was often seen as something related to their leisure activities in the garden, their domestic chores or walking as a means of transport. No one was involved in a specific aerobic or strengthening programme, and these beliefs might be a challenge to address and change within these communities (Angwenyi *et al.*, 2018).

As described by Angwenyi *et al.* (2018), patients tend to also explore the use of herbal medicine to assist with symptom management, especially when nothing else has worked or their PHC facility does not have the medicine in stock. The use of herbal medicine as an alternative pain management strategy was seen in all three the communities that were visited. This use of alternative strategies demonstrates their open-mindedness to explore new treatments and coping mechanisms, which will be a facilitator for their adherence and success when attending a self-management programme (Ali *et al.*, 2018). The use of herbal medicine is not currently included in clinical guidelines on self-management for knee OA, even though it is a context specific culture based intervention. The current evidence is however ambiguous on the topic of using herbal medicine for

management of OA related symptoms (Ernst & Posadzki, 2011) and the implications on the interaction with pharmacological management should be considered.

Although this was not the case in this particular study, Selman *et al.* (2009) found that some people prefer not to know anything about their condition. This was confirmed by Cuperus *et al.* (2013) who found that individuals who thought that nothing can be done for their OA, felt they do not require additional advice or information. Consequently, it should be considered that not all people would appreciate information about their condition, and could be a reason for someone not to attend self-management sessions. This view could affect their perception and management of the condition. However, for those who would like to know more, the mode of delivery of the content would play an essential role in their participation and personal benefit. In this study, there were mixed reports on who the participants felt should lead the programme. The majority of the participants in this study was open to the idea of having a peer trained for this specific task or even the community health care workers (CHCW). A fellow community member or the CHCW were seen as people they could relate to as well as having common interests. However, a small group of participants did not wish to have the CHCW involved as they felt that they were not the same as they used to be. This is in relation to the recent change in policy, where the CHCW's role changed to health promotion rather than caring for people in their homes. The popularity of the CHCW appeared to have declined as the people are still expecting full care from them, which might affect their participation in a programme led by the CHCW. Simultaneously, some participants were also sceptical of a peer-led programme due to the concern that some people might not approve of the chosen peer, and would prefer a professional with medical knowledge. However, it was recommended by the remaining majority that the community members with knee OA should be involved when choosing the peer who is sent for training. Even though the benefits of a physiotherapy led programme has been established (Saw *et al.*, 2016), it has been reported that having a trained peer supporter within the programme could be of great value to the patients (Lauckner & Hutchinson, 2016) and that the role of the CHCW within such a programme should not be underestimated (Angwenyi *et al.*, 2018). The information shared might feel more relevant when it is provided by a sympathetic peer they can relate to (Thorstensson *et al.*, 2015; Stenberg *et al.*, 2016). It is however, important to have a trained person responsible for supervising the programme, because a self-management programme that is dependent on the patients themselves, was found not effective when compared to attention control programmes (Kroon *et al.*, 2014).

Various forms of information delivery has been explored by previous self-management programmes, providing their patients with information booklets, relaxation DVD's, exercise DVD's, telephone interventions, web-based

sessions, etc. (Heyns, 2018). However, when presented with these options, the participants in this study felt that a booklet would best suit their needs. Similarly, Dube *et al.* (2017) found that individuals in a slightly different South African township setting also preferred a booklet they could read. These individuals stated that the book should not be too thick and must contain motivating pictures and information suited for low levels of literacy (Dube *et al.*, 2017). In addition, the participants of this study mentioned that they would not be able to watch a DVD, as a DVD player was a luxury not all of them could afford. Most of the participants were also not proficient in using a cellular phone or the internet, which would affect their ability to join telephone based interventions or a web based programme. Their lack of proficiency with items of technology (cell phone and internet), could be due to their age as 30% of the participants are over the age of 70 and have not yet learned the skill of using a cell phone. Their life situation has also prevented exposure to early forms of expensive technology, and their level of education might also contribute to their lack of proficiency. In addition, only 25% of participants owned a smart phone, which would inhibit delivery of self-management programmes on a cell phone application for the time being. As stated in section 2.3.4.3 digital literacy has been shown to affect the use of cellular phone based health interventions (Watkins *et al.*, 2018). Conversely, some suggestions made by the participants in the study by Dube *et al.* (2017), were the use of cellular phone messages, TV and radio programmes which could disseminate information. It should however also be recognized that a study in the Netherlands found that even though people had access to the “Care for Osteoarthritis” booklet, it was not widely used due to various barriers (Cuperus *et al.*, 2013). It is not certain if similar barriers would be found in the rural South African context, therefore a patient report study should be conducted after implementation to evaluate the effectiveness and use of the self-management information booklet.

5.6. Summary

In conclusion, the findings of this study was similar to the findings of a meta-synthesis by Schulman-Green *et al.* (2016) who found that various factors influences the successful implementation of a self-management programme for chronic diseases. The current knowledge and beliefs of the individuals along with their need for empowerment was found to be the most prominent personal factors that influenced their perspective on the management knee OA. It is therefore important to consider that information delivery should be congruent with the features of these specific communities, accounting for factors such as their language preferences, their information needs and their cultural beliefs. In the long term, integrated services using technology for interactive decision making, patient support tools and electronic health records such as those implemented in

Europe and Canada, could assist the management of chronic diseases such as OA, even in South Africa (Glasgow, Durand-Zaleski, Chan & Rubiano, 2008). Meanwhile, the contextual factors that would influence the implementation of a self-management programme in the rural areas of the Western Cape has been explored, and can now be used to create an intervention tailored to meet the needs of the individuals within this specific context.

Chapter 6

Conclusion

6.1. Conclusion

The aim of the study was achieved as the current contextual factors which could influence the implementation of a self-management and education programme for people with knee osteoarthritis (OA) living in the rural settings of the Western Cape, South Africa has been described. The results showed that the current services offered to individuals with knee OA living in rural areas of the Western Cape are not optimal and lacked a patient-centred approach. The needs identified were comparable with the components of a self-management and education programme, and a specific focus should be placed on the disease education and pain management skills. The most prominent contextual factors that could influence the implementation of a self-management intervention for knee OA in these areas were the personal factors related to ownership, compliance and social isolation which could influence their long term commitment to a self-management intervention. In addition, environmental factors such as the community attitudes, continuity of care and available transport could have an impact on their motivation and attendance.

The importance of contextualising evidence-based programmes from clinical practice guidelines were highlighted by this study, as the current self-management programmes for knee OA would not have been appropriate for direct use within the rural settings of the Western Cape. The identified contextual factors could therefore be used to adapt self-management programmes for knee OA as described by the current clinical practice guidelines for use in the rural areas of the Western Cape. As far as the primary investigator (PI) is aware, this was the first study in South Africa to investigate the contextual factors related to the implementation of a self-management and education programme for knee OA in the rural context.

6.2. Limitations

This study has certain limitations which should be considered when interpreting the findings. This study was only conducted in randomly chosen rural areas of the Western Cape. These rural areas are different from other rural communities in South Africa, therefore the results can only be considered for similar settings such as

those visited in this study. According to Flick (2009), one of the limitations to qualitative research includes the lack of generalisability of the results, as the sample are usually smaller than in quantitative research. In addition, the information gained are based on the thoughts and feelings of the participants interviewed at that specific time, by that specific researcher.

This study was gender biased due to the participation of only one male, which could have affected the results due to the lack of insight from males who might have different life roles and needs.

Exclusion of potential participants due to the recruitment is a possible limitation. Due to the snowballing and word of mouth recruitment, the PI relied on the memory and knowledge of the community members to identify possible candidates. However, the lack of a register or database for patients with musculoskeletal disorders reduced the options for recruitment.

It is also acknowledged that the translation of the transcriptions from Afrikaans to English could have altered the meaning of some of the sentences. Certain Afrikaans expressions were lost in translation, as no similar English word or phrase exists. The translation of the transcripts were done for the purpose of reporting the findings in English.

The perspective of other health care professionals were not sought and therefore not included due to the scope of the study.

It is acknowledged that the skill and the role of the PI could have influenced the disclosure of information by the participants (Britten *et al.*, 2006). The participants were aware that the PI is a physiotherapist and upon inquiry from the participants the PI also disclosed that this study formed part of a degree.

6.3. Recommendations

The use of a self-management programme is a low cost, long term maintenance plan for the management of chronic conditions such as OA of the knee, which could assist the clinicians in optimising their impact in a group setting, and building social support groups. Therefore, a self-management programme for knee OA such as used by Kruger-Jakins *et al.*, (2016) should be considered by clinicians and policy makers to address the needs of individuals with knee OA living in the rural areas of the Western Cape.

A feasibility study is recommended to ascertain a strategy for the implementation of such a programme and to find a reliable leader within these communities (such as the community health care workers or a trained peer). The use of educational booklets/ DVD's should be explored, focussing on a reliable source for the printing of booklets or producing the DVD's. It is also recommended that the views of the service providers be consulted and the mode of delivery be tested within these communities (Ernstzen *et al.*, 2017).

There is a need for an OA register in the South African health care context that should include patients who has different stages of OA to assist with monitoring of their progression as well as providing information for health related research which could improve the implementation of proven health care strategies.

It is also recommended, that in order to build a database of contextual information, the contextual factors for the implementation of a self-management and education programme in other rural areas of South Africa be explored, additional health related data be included, as well as a more detailed occupational history and disability grant status be included. The use of a self-reported health related quality of life tool should also be considered to provide further context. The qualifications of the community health care workers should be considered and the scope should also be extended to include other health care professionals. This database could then be used to compile a comprehensive, user friendly evidence-based product for use by clinicians and patients in the management of OA of the knee.

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APPENDIX A: ETHICS APPROVAL



UNIVERSITEIT
STELLENBOSCH
UNIVERSITY

Approved

New Application

Health Research Ethics Committee (HREC)

28/11/2017

Project Reference #: 1418

HREC Reference #: S17/09/172

Title: The contextual factors and relevance of guidelines on knee OA exercise and self-management interventions for people living in rural settings of the Western Cape: Proposal

Dear Ms Marisa Coetzee

The **New Application** received on 19/10/2017 14:36 was reviewed by the **Health Research Ethics Committee** via **expedited** review procedures on 28 Nov 2017 and was approved.

Please note the following information about your approved research protocol:

Protocol Approval Period: **This project has approval for 12 months from the date of this letter.**

Please remember to use your **project reference number (1418)** on any documents or correspondence with the HREC concerning your research protocol.

Please note that this decision will be ratified at the next HREC full committee meeting. HREC reserves the right to suspend the approval and to request changes or clarifications from applicants. The coordinator will notify the applicant (and if applicable, the supervisor) of the changes or suspension within 1 day of receiving the notice of suspension from HREC. HREC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

After Ethical Review

Please note you can submit your progress report through the online ethics application process, available at: <https://apply.ethics.sun.ac.za> and the application should be submitted to the Committee before the year has expired. Please see [Forms and Instructions](#) on our HREC website for guidance on how to submit a progress report.

The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly for an external audit.

Translation of the consent document(s) to the language(s) applicable to your study participants should now be submitted to the HREC.

Provincial and City of Cape Town Approval

Please note that for research at a primary or secondary healthcare facility, permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Please consult the Western Cape Government website for access to the online Health Research Approval Process, see: <https://www.westerncape.gov.za/general-publication/health-research-approval-process>. Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

We wish you the best as you conduct your research.

For standard HREC forms and instructions, please visit: [Forms and Instructions](#) on our HREC website (www.sun.ac.za/healthresearchethics)

If you have any questions or need further assistance, please contact the HREC office at 021 938 9677.

Yours sincerely,

Mr. Franklin Weber

Federal Wide Assurance Number: 00001372

Institutional Review Board (IRB) Number: IRB0005239

The Health Research Ethics Committee complies with the SA National Health Act No. 61 of 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 Part 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki and the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles, Structures and Processes 2015 (Department of Health).

APPENDIX B:

APPROVAL DEPARTMENT OF HEALTH – FRIEMERSHEIM



Health Impact Assessment
Health Research Sub Directorate
Health.Research@westerncape.gov.za
Tel: +27 21 483 0866; fax: +27 21 483 9895
5th Floor, Norton Rose House, 8 Riebeeck Street, Cape Town, 8001
www.capegateway.gov.za

REFERENCE: WC_201712_003
ENQUIRIES: [REDACTED]

Stellenbosch University
Faculty of Medicine & Health Sciences
Francie Van Zijl Drive
Tygerberg Hospital
Cape Town
7505

For attention: Mrs Marisa Coetzee

Re: The contextual factors and relevance of guidelines on knee OA exercise and self-management interventions for people living in rural settings of the Western Cape: Proposal

Thank you for submitting your proposal to undertake the above-mentioned study. We are pleased to inform you that the department has granted you approval for your research. Please contact the following people to assist you with any further enquiries in accessing the following sites:

[REDACTED] [REDACTED] [REDACTED]

Kindly ensure that the following are adhered to:

1. Arrangements can be made with managers, providing that normal activities at requested facilities are not interrupted.
2. Researchers, in accessing provincial health facilities, are expressing consent to provide the department with an electronic copy of the final feedback (**annexure 9**) within six months of completion of research. This can be submitted to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).

3. In the event where the research project goes beyond the *estimated completion date* which was submitted, researchers are expected to complete and submit a progress report (**Annexure 8**) to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).
4. The reference number above should be quoted in all future correspondence.

Yours sincerely



DIRECTOR: HEALTH IMPACT ASSESSMENT

DATE: 9 / 2 / 2018.

CC:



DIRECTOR: CENTRAL KAROO/ EDEN

APPENDIX C:

APPROVAL DEPARTMENT OF HEALTH – EBENHAEZER



**Health Impact Assessment
Health Research Sub Directorate**

Health.Research@westerncape.gov.za
Tel: +27 21 483 0866: fax: +27 21 483 9895
5th Floor, Norton Rose House, 8 Riebeeck Street, Cape Town, 8001
www.capegateway.gov.za

REFERENCE: WC 201712 003
ENQUIRIES: [REDACTED]

Stellenbosch University
Faculty of Medicine & Health Sciences
Francie Van Zijl Drive
Tygerberg Hospital
Cape Town
7505

For attention: Mrs Marisa Coetzee

Re: The contextual factors and relevance of guidelines on knee OA exercise and self-management interventions for people living in rural settings of the Western Cape: Proposal

Thank you for submitting your proposal to undertake the above-mentioned study. We are pleased to inform you that the department has granted you approval for your research. Please contact the following people to assist you with any further enquiries in accessing the following sites:

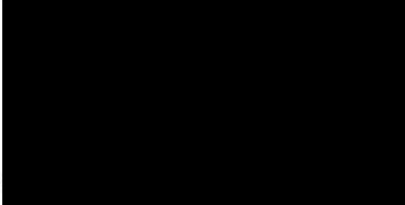
[REDACTED] [REDACTED] [REDACTED]

Kindly ensure that the following are adhered to:

1. Arrangements can be made with managers, providing that normal activities at requested facilities are not interrupted.
2. Researchers, in accessing provincial health facilities, are expressing consent to provide the department with an electronic copy of the final feedback (**annexure 9**) within six months of completion of research. This can be submitted to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).

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4. The reference number above should be quoted in all future correspondence.

Yours sincerely



DR A

DIRECTOR: HEALTH IMPACT ASSESSMENT

DATE: 13 / 2 / 2018

CC:



DIRECTOR: WEST COAST

APPENDIX D:

APPROVAL DEPARTMENT OF HEALTH – GENADENDAL



Health Impact Assessment
Health Research Sub Directorate
Health.Research@westerncape.gov.za
Tel: +27 21 483 0866; fax: +27 21 483 9895
5th Floor, Norton Rose House, 8 Riebeeck Street, Cape Town, 8001
www.capegateway.gov.za

REFERENCE: WC_201712_003

ENQUIRIES: [REDACTED]

Stellenbosch University
Faculty of Medicine & Health Sciences
Francie Van Zijl Drive
Tygerberg Hospital
Cape Town
7505

For attention: Mrs Marisa Coetzee

Re: The contextual factors and relevance of guidelines on knee OA exercise and self-management interventions for people living in rural settings of the Western Cape: Proposal

Thank you for submitting your proposal to undertake the above-mentioned study. We are pleased to inform you that the department has granted you approval for your research. Please contact the following people to assist you with any further enquiries in accessing the following sites:

[REDACTED] [REDACTED] [REDACTED]

Kindly ensure that the following are adhered to:

1. Arrangements can be made with managers, providing that normal activities at requested facilities are not interrupted.
2. Researchers, in accessing provincial health facilities, are expressing consent to provide the department with an electronic copy of the final feedback (**annexure 9**) within six months of completion of research. This can be submitted to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).

3. In the event where the research project goes beyond the *estimated completion* date which was submitted, researchers are expected to complete and submit a progress report (**Annexure 8**) to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).
4. The reference number above should be quoted in all future correspondence.

Yours sincerely



ACTING DIRECTOR: HEALTH IMPACT ASSESSMENT

DATE: 28-03-2018

CC:



DIRECTOR:



APPENDIX E:

INFORMED CONSENT FOR INDIVIDUAL INTERVIEWS

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM FOR PATIENTS.

TITLE OF THE RESEARCH PROJECT: The contextual factors and relevance of guidelines on knee OA exercise and self-management interventions for people living in rural settings of the Western Cape.

REFERENCE NUMBER: #1418

PRINCIPAL INVESTIGATOR: Marisa Coetzee

STUDY SUPERVISOR: Dr Linzette Morris

ADDRESS:

Physiotherapy Division Faculty of Medicine and Health Sciences Stellenbosch University
Francie van Zijl Drive; Tygerberg; Cape Town; 8000
South Africa

CONTACT DETAILS: 07# ### #### (Marisa Coetzee); (Dr Linzette Morris)

Dear Participant

My name is Marisa Coetzee and I am doing my Master's degree at the University of Stellenbosch. I would like to invite you to participate in a research project. This research project will focus on the contextual factors of a knee OA exercise and self-management programme as presented by the current guidelines for people living in rural settings of the Western Cape.

Please take some time to read the information in this letter, which will explain the details of the project and contact me if you require further explanation or clarification of any aspect of the study. Also, your participation in this project is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the **Health Research Ethics Committee (HREC) at Stellenbosch University** and will be conducted according to accepted and applicable National and International ethical guidelines and principles, including those of the international Declaration of Helsinki October 2008.

What is this research study all about?

The aim of this study is to identify how an exercise and self-management programme for knee Osteoarthritis, as described in the current clinical practice guidelines (CPG), could work in your setting, and to determine the relevance of such a guideline for the rural community of the Western Cape. CPG's are documents that medical personnel can use when they make decisions about specific conditions, such as knee OA. The information gained in this study could influence the use of knee OA guidelines by medical personnel in the primary health care (PHC) facilities (clinics or day hospitals in your area). It could also assist the medical personnel with implementing exercise and self-management programmes and activities in the community for people with knee OA.

Combined interviews with you and a family member will be held, at a place most convenient for you (e.g. at your house, at the clinic, in a community centre). The interview will be conducted in Afrikaans or English by myself, the primary investigator. If you are isiXhosa speaking, my research assistant will conduct the interview in my presence. In the interviews, we will discuss the current rehabilitation you are receiving from your local PHC facility/ clinic, as well as the specific factors within your community that could influence your participation in the current proposed exercise and self-management guidelines. The interviews will be approximately 1 hour long, and will be recorded with a digital voice recorder.

If a direct statement made by one of the people participating in the study is used in the report, the name of this person will not be mentioned. They will be referred to as "patient 1", "patient 2", "family member 1", "family member 2", and so on.

Why have you been invited to take part?

You have been asked to take part if:

- You are living in a rural area (as defined by the Western Cape Government).
- You are a patient attending the PHC facility/ clinic in your area for treatment of your knee OA.
- You were available for interviewing and willing to take part.

What will your responsibilities be?

If you agree to take part, you will be asked to give feedback on the current rehabilitation you receive at your clinic, as well as answer truthfully about the contextual factors (factors specific to your environment and community) that could influence your participation in an exercise and self-management programme.

Will you benefit from taking part in this research?

The benefits of the information obtained in this study could allow for deeper insight and consideration for the value of the rehabilitation to the life of the patient as well as the contextualising factors involved in rehabilitation at PHC level when using an exercise and self-management programme. This could lead to improved patient care.

Are there in risks involved in you taking part in this research?

There are no identified risks involved in participating in this study.

Who will have access to your records?

All information collected during the study will be treated as confidential and protected. If any direct comments from the people who take part are used, the person will not be identified. Only the researcher will have access to specific information. The recorded information will be typed out but no names will be given on the recorded information. The completed report will be published in a medical journal.

Will you be paid to take part in this study and are there any costs involved?

No, you will not be paid to take part in the study but your time and efforts will be thanked with a food basket. There will be no costs involved for you.

Is there anything else that you should know or do?

You can contact the Health Research Ethics Committee at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed.

You will receive a copy of this information and consent form for your own records.

If you are willing to participate in this study please sign the attached Declaration of Consent and hand it to the investigator.

Yours sincerely

Marisa Coetzee

Principal Investigator

Declaration of consent by participant

By signing below, I agree to take part in a research study entitled **The contextual factors and relevance of guidelines on knee OA exercise and self-management interventions for people living in rural settings of the Western Cape.**

I declare that:

- I have read the attached information leaflet and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) On (*date*) 2018.

.....

Signature of participant

Declaration by investigator

I (*name*) declare that:

- I explained the information in this document to
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did/did not use an interpreter. (If an interpreter is used then the interpreter must sign the declaration below.

Signed at (*place*) on (*date*) 2018.

.....

Signature of investigator

.....

Signature of witness

APPENDIX F:

INFORMED CONSENT FOR FOCUS GROUP INTERVIEWS

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM FOR COMMUNITY HEALTH CARE WORKERS.

TITLE OF THE RESEARCH PROJECT: The contextual factors and relevance of guidelines on knee OA exercise and self-management interventions for people living in rural settings of the Western Cape.

REFERENCE NUMBER: #1418

PRINCIPAL INVESTIGATOR: Marisa Coetzee

STUDY SUPERVISOR: Dr Linzette Morris

ADDRESS:

Physiotherapy Division Faculty of Medicine and Health Sciences Stellenbosch University

Francie van Zijl Drive; Tygerberg; Cape Town; 8000

South Africa

CONTACT DETAILS: 07# ### #### (Marisa Coetzee); (Dr Linzette Morris)

Dear Participant

My name is Marisa Coetzee and I am doing my Master's degree at the University of Stellenbosch. I would like to invite you to participate in a research project. This research project will focus on the contextual factors of a knee OA exercise and self-management programme as presented by the current guidelines for people living in rural settings of the Western Cape.

Please take some time to read the information in this letter, which will explain the details of the project and contact me if you require further explanation or clarification of any aspect of the study. Also, your participation in this project is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the **Health Research Ethics Committee (HREC) at Stellenbosch University** and will be conducted according to accepted and applicable National and International ethical guidelines and principles, including those of the international Declaration of Helsinki October 2008.

What is this research study all about?

The aim of this study is to identify how an exercise and self-management programme for knee Osteoarthritis, as described in the current clinical practice guidelines (CPG), could work in your setting, and to determine the relevance of such a guideline for the rural community of the Western Cape. CPG's are documents that medical personnel can use when they make decisions about specific conditions, such as knee OA. The information gained in this study could influence the use of knee OA guidelines by medical personnel in the primary health care facilities (clinics in your area). It could also assist the medical personnel with implementing exercise and self-management programmes and activities in the community for people with knee OA.

A focus group discussion will be held with all of the community health workers, at a place most convenient for you (e.g. at the clinic/ at a community centre). The interview will be conducted in Afrikaans or English by myself, the primary investigator. If you are isiXhosa speaking, my research assistant will conduct the interview in my presence. In the discussion, we will talk about the current rehabilitation available at the local PHC facility/ clinic, as well as the specific factors within your community that could influence the participation of the people with knee OA in the current proposed exercise and self-management guidelines. The interviews will be approximately 1 hour long, and will be recorded with a digital voice recorder.

If a direct statement made by one of the people participating in the study is used in the report, the name of this person will not be mentioned. They will be referred to as "community worker 1", "community worker 2", and so on.

Why have you been invited to take part?

You have been asked to take part if:

- You are working as a community health care worker in a rural area (as identified by the Western Cape Government).
- You were available for interviewing and willing to take part.

What will your responsibilities be?

If you agree to take part, you will be asked to give your opinion on the contextual factors (factors specific to your environmental and community) that could influence the participation of the people in the community living with knee OA. You are expected to answer truthfully on all questions asked.

Will you benefit from taking part in this research?

The benefits of the information obtained in this study could allow for deeper insight and consideration for the value of the rehabilitation to the life of the patient as well as the contextualising factors involved in rehabilitation at PHC level when using an exercise and self-management programme. This could lead to improved patient care.

Are there in risks involved in you taking part in this research?

There are no identified risks involved in participating in this study.

Who will have access to your records?

All information collected during the study will be treated as confidential and protected. If any direct comments from the people who take part are used, the person will not be identified. Only the researcher will have access to specific information. The recorded information will be typed out but no names will be given on the recorded information. The completed report will be published in a medical journal.

Will you be paid to take part in this study and are there any costs involved?

No, you will not be paid to take part in the study but your time and efforts will be thanked with a food voucher. There will be no costs involved for you.

Is there anything else that you should know or do?

You can contact the Health Research Ethics Committee at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed.

You will receive a copy of this information and consent form for your own records.

If you are willing to participate in this study please sign the attached Declaration of Consent and hand it to the investigator.

Yours sincerely

Marisa Coetzee

Principal Investigator

Declaration by participant

By signing below, I agree to take part in a research study entitled **The contextual factors and relevance of guidelines on knee OA exercise and self-management interventions for people living in rural settings of the Western Cape.**

I declare that:

- I have read the attached information leaflet and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) On (*date*) 2009.

.....

Signature of participant

Declaration by investigator

I (*name*) declare that:

- I explained the information in this document to
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did/did not use an interpreter. (If an interpreter is used then the interpreter must sign the declaration below.

Signed at (*place*) on (*date*) 2017.

.....

Signature of investigator

.....

Signature of witness

APPENDIX G: INTERVIEW STRUCTURE FOR INDIVIDUAL INTERVIEWS

Done	Subject	Comments
<i>How has your life been affected by the knee OA? What changed in your life? What are you struggling with now?</i>		
	Mobility: Walking inside (standing, sitting, walk) Walking outside (stairs) Walking in the community Travelling (in and out of a vehicle) Trust in the knee	
	Activities of daily living: Personal hygiene (bath, shower, dressing) Domestic chores inside Domestic chores outside Community (groceries)	
	Social: Friends Community activities/ groups Relaxation and hobbies	
	Work	
<i>What are you currently receiving as treatment for your knee OA?</i>		
	Current rehabilitation: Information on OA (what, progression) Options for treatment (alternative) Exercises to do (and the NB) Exercises not to do Home programme Training on symptom management Types of pain Pain management (medication etc) Weightloss Support (from health carers) Assistive devices	

	Community workers Is it working? What would you like to receive?	
	Services: Doctor Nurse PT OT	
	Environment: Safety Structurally Transport PHC clinic	
	Support: Family Friends Community Groups for walking	
	Willingness/ eagerness Doing own exercises Would like to partake in group Group leader: CHCW Group leader: patient Group leader: PT	
	Self help Book App CD/DVD	

Additional comments

APPENDIX H: INTERVIEW STRUCTURE FOR FOCUS GROUP DISCUSSIONS

Done	Subject	Comments
	<i>How do you see your role in the community?</i>	
	How do you find the current rehabilitation structure in the community?	
	Access to: Information on OA (what, progression) Options for treatment (alternative) Exercises to do (and the NB) Exercises not to do Home programme Training on symptom management Types of pain Pain management (medication etc) Weightloss Support (from health carers) Assistive devices	
	Environment: Safety Structurally Transport PHC clinic	
	Support: Family Friends Community Groups for walking (current and future)	
	Willingness/ eagerness Doing own exercises Would like to partake in group/ individual Group leader	
	Self help Book	

	App CD/DVD	
Community togetherness? (teamwork/ division)		
	Would you be able to lead such a programme? Presentation of info Exercise supervision Time for such a programme in your schedule?	
	Service centre (elderly) If they present it	
	Will people be willing to do this with you? (vs PT or OT or community champion) Group leader: patient Group leader: PT	
	What could be a barrier? What could be a facilitator?	

APPENDIX I: DEMOGRAPHIC

QUESTIONNAIRE FOR INDIVIDUAL PARTICIPANTS

Study ID no: _____

Date: _____

Participant number:	
Age:	
Gender:	Male / Female
Can you read?	Yes / No
Language?	Afrikaans / English / IsiXhosa / Other
How long have you been diagnosed with OA?	
Are you receiving Rehabilitation?	Yes / No
How often do you go for Physiotherapy or Occupational Therapy?	
How do you travel to the PHC?	Walk / Car / Train / Taxi / Bus
Do you miss a day of work when going to the clinic?	Yes / No
Does the PT or OT do home visits?	Yes / No
Do you see any other medical people at the PHC?	Doctor / Nurse / Dietician / Other
Are there community workers that could come to your house?	Yes / No
Do you work?	Yes / No
What type of work do you do/ did you previously do?	
Do you have electricity?	Yes / No
DO you have a cellphone?	Yes / No
Do you have a DVD player/ CD player?	Yes / No
Level of education?	

APPENDIX J: DEMOGRAPHIC

QUESTIONNAIRE FOR FOCUS GROUP PARTICIPANTS

Date: _____

Participant number:						
Age:						
Gender:						
Home language						
How long have you been a CHCW in this area?						

APPENDIX K: CODE BOOK

Topic	Code name	Description
Impairments to body function		
Movement related function	BF_mobility_joints	Mobility issues specifically related to <i>joint structure</i> e.g. stiffness, swelling, pain
	BF_mobility_night	Mobility related issues specifically related to symptoms and function during the <i>night time</i>
	BF_mobility_day	Mobility related issues specifically related to symptoms and function during the <i>day time</i>
Activity and Participation		
Mobility	AP_mobility_walking_short	Mobility related issues <i>affecting walking</i> over short distances (around the house and to the neighbours) as stated by the participant
	AP_mobility_walking_long	Mobility related issues <i>affecting walking</i> over longer distances (within the community to visit clinic, friends and go to church and shop) as stated by the participant
	AP_mobility_transfers	Mobility related issues <i>affecting positional transfers</i> as stated by the participant (such as sit to stand)
	AP_mobility_standing	Mobility related issues affecting their <i>ability to stand for prolonged periods of time</i> as stated by the participant
	AP_mobility_stairs	Mobility related issues affecting their <i>ability to climb stairs</i> as stated by the participant
	AP_mobility_transport	Mobility related issues affecting their <i>ability to use public transport</i> (taxi, train, car, bus etc.)
	AP_mobility_sitting	Mobility related issues in the <i>sitting</i> posture, such as sitting for long periods of time
Activities of daily living	AP_ADL_SC	<i>Self care: ability</i> of the participant to <i>care for themselves</i> (washing, shower, dressing, acquiring health services etc.), as well as sleep.
	AP_ADL_caring	Ability of the participant to <i>take care of others</i> (spouse, children, grandchildren)
Domestic life	AP_domestic_in	Ability of the participant to perform <i>domestic chores inside</i> the house (cleaning, bending, laundry, cooking etc.)
	AP_domestic_out	Ability of the participant to perform <i>domestic chores outside</i> the house (home maintenance tasks etc.)
	AP_domestic_shopping	Ability of the participants to do the <i>grocery shopping</i>
Community	AP_community	Ability of the participant to <i>participate in community related activities</i> (visit the clinic, church etc.)
Social	AP_social_groups	Effect of their condition on the participation in <i>community/ social group activities</i>
	AP_social_friends	Effect of the condition on their participation in <i>social activities with their friends</i>
Leisure and recreation	AP_leisure	Effect of the condition on their ability to <i>partake</i> in their favourite <i>leisure activities</i> (gardening, knitting etc)
Occupation	AP_occupation	Effect of the condition on their ability to <i>perform work related tasks</i>

Contextual: Environmental factors		
Product and Technology	EF_PT_AD	<i>Assistive devices</i> used for mobility in daily life
	EF_PT_buildings	<i>Buildings</i> available for use by the community
Natural environment	EF_climate	Effect of the <i>climate</i> on the ability of the individual to <i>participate in general activities</i>
	EF_terrain	All variables related to the natural <i>terrain</i> in the area
Support and relationships	EF_SR_Family	Support provided by the <i>family</i> members (spouse, children, brothers, uncles etc.) living with them in their house/ on their property
	EF_SR_friends	<i>Support</i> provided by their <i>friends</i>
	EF_SR_community	<i>Support</i> provided by their <i>neighbours, peers, acquaintances</i> within the area they live
	EF_SR_HP	Support provided by the <i>health professionals</i> in their community (clinic personnel)
	EF_SR_CHCW	Support provided by the <i>community health care workers</i> in their community
Attitudes	EF_att_family	<i>Attitudes</i> of their <i>family members</i> (immediate and extended) related to beliefs, values and norms around the participant
	EF_att_community	<i>Attitudes</i> of the community (<i>neighbours, peers, friends</i>) related to beliefs, values and norms around the participant
	EF_att_HP	<i>Attitudes</i> of the <i>health professionals</i> related to beliefs, values and norms around the participant
Services, systems and policies	EF_SSP_HS_education	<i>Health services</i> provided related to <i>education</i> on the condition, the treatment options, as well as general lifestyle changes.
	EF_SSP_HS_exercise	<i>Health services</i> related to the provision of <i>exercises</i> and functional rehabilitation and a home program
	EF_SSP_HS_pmx	<i>Health services</i> related to the management of <i>symptoms</i> (such as pain and swelling)
	EF_SSP_HS_AD	Received <i>assistive devices</i> from the <i>health system</i>
	EF_SSP_HS_needs	The <i>needs</i> of the participant with relation to <i>health services</i> as perceived by themselves
	EF_SSP_HS_nurse	<i>Services</i> acquired from the <i>nurse</i> for their condition
	EF_SSP_HS_doctor	<i>Services</i> acquired from the <i>doctor</i> for their condition (local or specialist)
	EF_SSP_HS_PT	<i>Services</i> acquired from the <i>physiotherapist</i> for their condition
	EF_SSP_HS_OT	<i>Services</i> acquired from the <i>occupational therapist</i> for their condition
	EF_SSP_HP_DT	<i>Services</i> acquired from the <i>dietician</i> for their condition
	EF_SSP_HP_CHCW	<i>Services</i> acquired from the <i>community health care workers</i> for their condition
	EF_SSP_transport	<i>Transport services</i> available to the participant within their community
Security	EF_security	<i>Security</i> related aspects within their community (affecting their ability to participate in their own health care)

Contextual: Personal factors (Grotkamp <i>et al.</i> , 2012)		
Mental factors	PF_mental_reliability	How reliable would this person be in terms of attending a programme and doing exercises as prescribed
	PF_mental_new	Openness to new experiences (would this person be interested in trying out new things with regards to their rehabilitation programme- willingness to change)
	PF_mental_optimism	Optimism towards group therapy and working with other people
	PF_CF_memory	Storing and retrieving of information
Attitudes	PF_att_health	Attitude of the participants towards their own health and the rehabilitation and treatment thereof
	PF_att_HC	Attitude of the participant towards intervention, related to medication, surgery and rehabilitation (health care)
	PF_att_compliance	Compliance to treatment
	PF_att_confidence	Confidence in their body (knee) to perform their ADL's, including balance related confidence
	PF_att_help	Attitude of the participant towards assistance from others
	PF_att_society	Attitude of the participant towards society (do they feel obliged to make contributions or do they feel society owe them support)
	PF_att_self worth	Attitude related to their own self worth/ how they feel about themselves
Empowerment	PF_E_motivation	Motivation to take care of one self and willingness to partake in community intervention
	PF_E_independence	Independence of the participant within their daily life
	PF_E_SM	Motivation of the participant to manage their own condition (self-management), pace themselves and their dependence on health care
	PF_E_adaptations	The ability of the participant to adapt things in their lives, in order to continue with their ADL's etc.
Behavioural factors	PF_BF_EH	Exercise habits of the individual (positive or negative)
	PF_BF_RH	Relaxation habits of the individual, taking time to relax and look after their own health
Implementation		
Group leader	I_GL_CHCW	Group leader: community health care worker
	I_GL_CC	Group leader: community champion
	I_GL_PT	Group leader: Physiotherapist
	I_GL_students	Group leader: students (exchange students in community)
Content	I_C_book	Content presented in a book format
	I_C_CD/DVD	Content presented on a DVD/CD
	I_C_App	Content presented in a cell phone application
Time	I_time	Implementation of group related to time (specific and frequency)
Venue	I_venue	Implementation of group related to venue

Barriers	I_B	Implementation barriers as seen by the participant
Facilitators	I_F	Implementation facilitators as seen by the participant
Extras		
	Ex_boerate	All the extra self-management tactics used by the participants to care for their symptoms, including community education as given by their fellow community members

APPENDIX L: EXAMPLES OF CODES USED

Document	Quotation number	Codes	Quotations
12	12:70	EF_SSP_HS_DT EF_SSP_HS_doctor EF_SSP_HS_education Facilitators/ positive	"Yes. I get into trouble about that here at the clinic. You must eat less. The doctor is firm; you must eat less look at what you look like, your knees can't carry your body."
24	24:57	EF_SSP_HP_CHCW EF_SSP_HS_DT EF_SSP_HS_education Facilitators/ positive	"Especially if we see that there is a problem with weight or pain or that sort of thing, then we would encourage the person, the less you weigh the less weight there is on the painful area. Foot or knee or so, and that helps a lot."
5	5:1	Barrier/ negative BF_mobility_joints PF_att_self worth PF_E_motivation	"I don't feel myself anymore. Four years ago I could still do everything, but I feel with the arthritis a part of my life is missing because the things I could do, I can't do anymore."
9	9:30	Barrier/negative EF_SR_HP PF_att_HC	"Uh-uh. There's not much support from the clinic. Because you see, when you get there then they ask you what's the problem but they don't do anything about it. They just tell you they don't have tablets, or they don't have this or that, then you just have to go home again, and walk all the way back"
11	11:62	EF_att_community I_B PF_att_help	"The people are very funny. I don't understand them and that's why I say I don't take notice of the community because they like looking down on the simple ones."
10	10:50	Barrier/negative EF_att_community EF_SR_friends PF_att_society	"We are not really people who like to mix with other people. So you can't expect people to visit and we all sit and chat together on a daily basis because we don't like it."
24	24:85	EF_SR_community Facilitator/positive I_F PF_att_compliance	"This is a close community. The reason why, everyone is family. Everyone knows everyone. If you are family or not, everyone knows you, so the support. Come one Saturday to a funeral in Genadendal, then you will see everyone there."
10	10:71	EF_SR_community I_F PF_menatl_optimism	"We would talk about our problems, not about other people, just your own problems. And then we sit and chat. But we would encourage one another. It was nice."

APPENDIX M: EXAMPLES OF TRANSLATIONS

Quotation Afrikaans: Original	Quotation English: Translated
"Al is dit ook wat ek moet gewig verloor, sal ek dit ook doen, maar gee my net 'n voorskrif vir die hoe ek moet eet en daardie, dan sal ek dit ook doen." (Deelnemer 7; >20jr)	"Even if it's to lose weight I will also do it. But just give me a prescription of how I should have to lose weight, I'll do it too, but just prescribe on how I should eat, I will do it." (Participant 7; >20yrs)
"Sien ek vir dokter eers oor twee weke. Nou moet ek vir Fisio sien na dokter, nou moet ek weer nog 'n maand of twee maande wag om vir fisio te sien. Intussen is my knie tot niet teen die tyd wat ek by die fisio kom." (Deelnemer FG17)	"I only get to see the doctor in two weeks. Now I must see the physio after doctor, now I wait for another month or two. In the meantime my knee is destroyed by the time I get to see the physio." (Participant FG17)
"Kyk ek loop mos nou nie meer nie. Ek loop nie na die mense toe nie, ek kan nie meer loop nie. Daardie tyd het ek baie geloop, gaan erte pluk, gaan bone pluk en al daardie goete gaan doen maar nou kan ek dit nie meer doen nie. Ek sit maar net hier by die huis." (Deelnemer; >20jr)	"You see, I don't walk anymore, and I don't go to visit people anymore... I used to walk a lot, picking peas, beans and all those things, but now I can't do it anymore. I just stay at home now." (Participant 10; >20yrs)
"En die man gaan net met daai gedagte, op die ou end van die dag gaan ek nie gesond raak nie, so al gaan dit 'n bietjie beter, wat baat dit ek gaan dan? Dan kan ek maar by die huis gesit het en by die huis oefeninge gedoen het. As wat ek nou so ver moet stap na 'n ondersteunings groep toe waar ons almal bymekaar kom." (Deelnemer FG7)	"And the man will go with that thought that at the end of the day it is not going to make me better, so even if it does improve a little, what will I gain in attending. Then I could just sit at home and do my exercises at home. Rather than having to walk that far to attend a support group where we all get together" (Participant FG7)
"Want as daar vergoeding is dan sal die ding langer instand gehou word maar as die man nie vergoeding kry nie dan gaan hy een en twee keer kom dan gaan hy, ag ek kry niks daarvoor nie, waarvoor moet ek gaan?" (Deelnemer; 4jr)	"Because compensation may help to sustain this, and if the person doesn't receive compensation he may come once or twice and then think, I'm not getting anything for this, why must I go. Nowadays people no longer work for free." (Participant 6; 4yrs)
"Ja, jy moet saam gaan. En as ek nou die probleem het en ek sukkel nou. My buurvrou weet ek wil baie graag daar wees maar sy het nie daai probleem nie, sy sal my help om daar te kom of my niggie gaan my kom haal, of daai nefie gaan my neem. So die families se support is daar." (Deelnemer FG17)	"Yes, you must go with. And if I have this problem and I am struggling. My neighbour knows I really want to be there, but she does not have that problem, she will help me get there, or my cousin will come and take me. So the family support are there." (Participant FG17)

APPENDIX N: PHOTOS AND DISCRIPTION OF SETTINGS

Ebenhaezer

A surprisingly large area close to Vredendal and Klawer on the West Coast. It consisted of a mixture of paved and unpaved roads between the widely spread areas of housing. There was a substantial difference between the socio-economic appearances of the areas, varying between large brick houses and smaller one room government funded brick houses. Some of the community members also farmed on small scale with animals in the area outside of the main town. The streets were clean and quiet during the day and most of the activity took place close to the clinic, library and shop. The town felt somewhat deserted in the morning when all the children were in school and the adults at work. Figure below: top left to right: the clinic in the area and the unpaved roads; bottom left to right: paved roads and the small scale farming practices in the area.



Figure: Ebenhaezer

Friemersheim

This town is fairly small and green with lots of trees, gardens and paved roads. The clinic and church are situated level with the incoming road, however the rest of the town slopes downwards towards a stream and then up again on the other side. These hills are tedious to walk when one is visiting the clinic, especially for the individuals with physical impairments. Most people had lovely edible gardens, with goats, dogs and cows roaming the streets. It was a very clean town and the streets had a fair amount of activity with people walking between houses, visiting their friends and the clinic. There is also a sewing group, a library, a primary school and at the time of data collection road works which created jobs for the local community. The town had an inviting atmosphere and a sense of slow living.

Figure below: top left to right: the library garden, some houses and local sewing project building; bottom left to right: the local clinic and the steep roads in the area.



Figure: Friemersheim

Genadendal

This town is situated in the Overberg district close to a large mountain range. The main road was paved, but most of the side streets were unpaved and the house properties were somewhat smaller than the ones seen at the other two areas visited. The layout of the town was in an elongated shape, and the clinic and shop was situated at the one end, making walking to the clinic increasingly further and more cumbersome for the residents at the other end of the town. Horses were roaming the streets and the overall feel of the town was lively and busy.

Figure below: top left to right: isolated houses and grocery stores with horses in the street; bottom left to right: main road of the town and entrance to Genadendal showcasing its historical missionary origins.

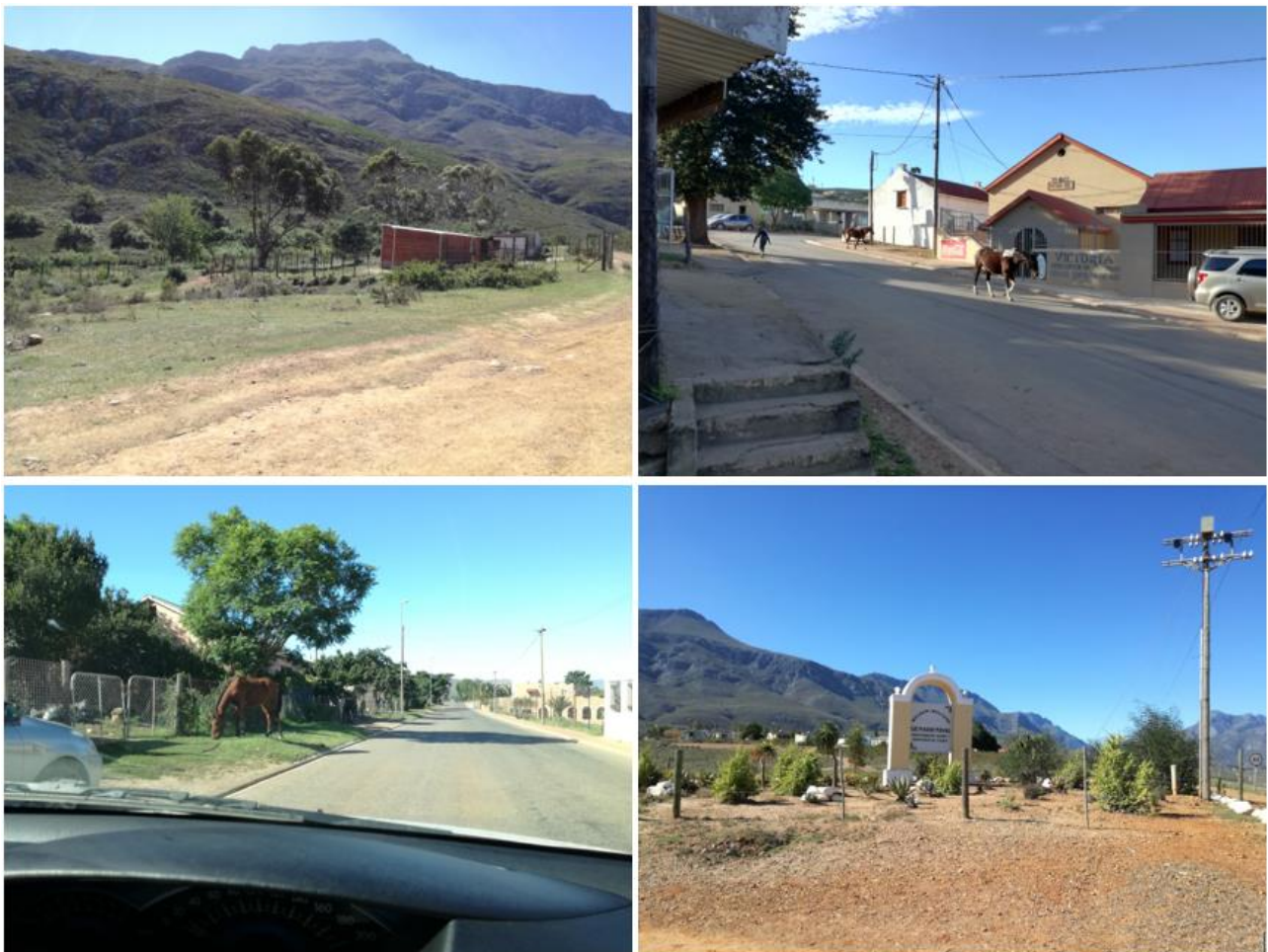


Figure: Genadendal